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A Capabilities Approach to Understanding Health Disparities

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A Capabilities Approach to Understanding Health Disparities

by

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Dedication

This dissertation is dedicated to those among us who struggle to be heard. This is my attempt to amplify their voices.

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Abstract

A Capabilities Approach to Understanding Health Disparities

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Supervisor: Tracie C. Harrison

Health disparities are pervasive in the U.S., and three of the greatest risk factors for poor health outcomes are race, rural residence, and disability. Individuals in these groups frequently experience poor health outcomes and social disadvantages. Such disadvantages contradict ethical principles such as respect for equal moral worth of all and social values such as non-discrimination. The purpose of this dissertation was to explore race, disability, rural culture, and disparities experienced by these groups using a social justice lens. Specifically, this dissertation relies upon a social constructionist perspective situated within Sen's capabilities approach to examine the cultural and social systems that influence the meaning and experience of health, well-being, and disability. The dissertation is comprised of three separate manuscripts; each presents findings from a distinct investigation. The first is an issue brief that answers the research question: how does the capabilities approach compare with the WHO's *International Classification of Functioning, Disability, and Health* (ICF) in terms of these models' ability to accommodate the diverse experiences and needs of people with disabilities? The second presents results from a critical analysis of literature related to racial disparities in healthcare utilization and outcomes among veterans in the Veterans' Healthcare

Administration (VHA). This investigation answers the research question: what are the structural determinants that influence disparities in health between African-American veterans and their non-Hispanic white counterparts with osteoarthritis? The third presents findings from a grounded theory study investigating well-being among working-age adults with disabilities living in rural counties in Texas. This investigation of 12 rural-dwelling adults with disabilities answers the research questions: how do working-age adults with disabilities who live in rural Texas define and pursue well-being, and how does the rural environment influence both their definition of and their ability to pursue well-being? The findings from this dissertation underscore the critical notion that individuals are inextricable from their social worlds. It is argued that without a holistic assessment of an individual's sociocultural and economic circumstances, healthcare providers may inadvertently perpetuate disparities by providing culturally inappropriate care and/or prescribing physically or economically unattainable interventions. Implications for nursing practice, policy, and the delivery of long-term services and supports in rural areas are discussed.

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Chapter 1: Introduction

Health disparities are persistent and pervasive in the United States. Health disparities are defined as "potentially avoidable differences in health that adversely affect socially disadvantaged groups and groups that have experienced discrimination or social exclusion" (Braveman et al., 2011, p. S150). Thus, depending upon an individual's membership in particular social groups, he or she may be at risk of experiencing health disparities and not achieving their full health status. Health disparities are problematic because they contradict human rights principles such as the inherent moral worth of all individuals (Nussbaum, 2006; Yamin, 2009) as well as deeply held social values such as non-discrimination (Braveman & Gruskin, 2003). Further, health disparities produce avoidable suffering, lost productivity, and wasted human resources (Smith, 2007). Indeed, it has been estimated that eliminating health disparities would have reduced direct medical care expenditures by $229.4 billion and indirect costs associated with illness and premature death by nearly $1 trillion during 2003-2006 (LaViest, Gaskin, & Richard, 2011).

DISSERTATION PURPOSE

The purpose of this dissertation is to identify and provide theoretical justification for sociocultural factors that result in increased risk for members of specific social groups—African Americans, rural residents, and adults with disabilities—for experiencing health disparities. Ultimately, findings from this research are intended to contribute to the evidence base regarding socially-situated origins of inequitable levels of health and well-being in the United States. Results can be used to develop culturally-

relevant and person-centered healthcare interventions and policy solutions in order to reduce health disparities, lower healthcare costs, and reduce human suffering.

BACKGROUND AND SIGNIFICANCE

In the United States, three of the greatest risk factors for poor health are race, rural residence, and disability. African Americans experience disproportionately poor health outcomes compared to other racial groups. Indeed, racial disparities between African American and non-Hispanic white populations are evident in the incidence, severity, and progression of chronic illness even when controlling for risk factors (Williams, 2012). Consequently, African Americans have been estimated to have an overall mortality rate 30 percent higher than that of whites (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). African Americans are also the racial group most likely to report complex activity limitations defined as restrictions in the ability to participate fully in social role activities (such as working, maintaining a household, engaging in social activities, or self-care tasks) (Altman & Bernstein, 2008).

Rural residence is another risk factor associated with poor health outcomes. For example, research has identified substantial and increasing urban-rural disparities in life expectancy over time. In 1969-1971, the gap was 0.4 years; in 2005-2009, it had widened to 2.0 years (Singh & Siapush, 2014). Nationwide, the highest all-cause mortality rates for working-age adults are found in the most rural counties (Meit et al. 2014). This pattern holds true for ischemic heart disease, chronic obstructive pulmonary disease, unintentional injury, and suicide (Meit et al. 2014). Researchers have also identified higher disability rates across gender, race, impairment type, and all age groups in the most rural nonmetropolitan counties in the United States (RTC Rural, 2017). For instance, in a study comparing rural and urban residents with chronic low back pain,

Goode, Freburger, and Carey (2013) found that rural residents reported higher levels of functional limitation and depression. Additionally, rural veterans with mental illness have been found to experience a greater disease burden than their urban counterparts (Wallace, Weeks, Wang, Lee, & Kazis, 2006**).**

In this dissertation, disability is used in accordance with the *International Classification of Functioning, Disability, and Health* (ICF) (World Health Organization [WHO], 2001). That is, disability is an umbrella term encompassing the interacting domains of impairments and limitations in activities and participation mediated by environmental and personal factors (WHO, 2001). Shortcomings of this classification will be presented and analyzed, but the ICF has broad utility for health outcomes research and population surveys, and it has provided an organizational basis for social policy (Imrie, 2004). Thus, it is useful for this dissertation which uses a social constructionist perspective and investigates disability from multiple perspectives.

Living with a disability produces an additional element of risk for the possibility of experiencing poor health. For example, using data from the National Health Interview Survey (NHIS), Carroll and colleagues (2014) found that adults with disabilities (See Table 1 for measures of disability) were found to be three times more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities. While it is true that many disabilities result from chronic illness such as stroke or diabetes, evidence indicates that people with lifelong disabilities experience health disparities. Dixon-Ibarra and Horner-Johnson (2014) also used NHIS data and identified that after controlling for age, sex, race/ethnicity, marital status, and working status, people with lifelong disabilities had significantly higher odds of coronary heart disease, cancer, diabetes, and hypertension. This evidence suggests that health disparities experienced by adults with disabilities cannot be solely attributed to underlying medical diagnoses or conditions.

Importantly, these groups are also at higher risk for disparities in important social indicators such as educational attainment, employment, and income. Using data from the NHIS, Braveman and colleagues (2010) found that, on average, and compared to the non-Hispanic white population, African Americans were more likely to have not graduated high school (20.7% vs. 11.1%) and were less likely to have graduated from college (16.8% vs. 30%). Similarly, people living in rural areas are less likely than their urban counterparts to have earned a Bachelor's degree or higher (19% vs. 33%) (U.S. Department of Agriculture, 2017). In 2017, the unemployment rate for African Americans was 7.7 percent compared to the national rate of 4.4 percent and the rate for whites of 3.9 percent (Brainard, 2017). Further, compared with the non-Hispanic white population, African Americans have lower income earnings at comparable levels of education, less wealth at every level of income, and in 2013, the wealth of white households was 13 times the median wealth of African American households (Kochhar & Fry, 2014). And, the overall rate of poverty is higher in nonmetropolitan than in metropolitan areas in the United States (Cromartie, 2017).

Using data from the NHIS, Stevens and colleagues (2016) found that regardless of type of disability, when compared to those without disability, adults with disability were significantly more likely to have less than a high school diploma (26.9% vs. 13.1%) and, accordingly, significantly less likely to have a college degree (14.9% vs. 35.1%) (Stevens et al., 2016). Further, regardless of how disability is measured, in the United States, the employment rate of working-age adults with disabilities is significantly lower than the rest of the working-age population (Stapleton, O'Day, Livermore, & Imparato, 2006). According to estimates from the Current Population Survey, in 2016, 17.9 percent of people with disabilities were employed compared to 65.3 percent of those without disabilities (U.S. Department of Labor, 2017). Perhaps not surprisingly, the poverty rate

for people aged 18-64 with disabilities was 28.4% in 2012—compared to the poverty rate of 12.5% for people in the same age category without a disability (DeNavas-Walt, Proctor, & Smith, 2012).

The aforementioned social indicators—that is, factors outside of the healthcare system—have been repeatedly associated with health outcomes. For example, income has a well-established association with health: evidence indicates that in the U.S., adults living in poverty are more than five times as likely to report being in fair or poor health as adults with incomes at least four times the federal poverty level (Braveman & Egerter, 2008). Other researchers estimate that living on incomes of less than 200% of the federal poverty level has a larger effect on health outcomes and mortality than tobacco use and obesity (Muennig, Fiscella, Tancredi, & Franks, 2010). Education is also associated with health. Evidence indicates that adults without a high school diploma or GED are three times as likely as those with at least some college education to die before age 65 (Heron et al., 2009), and life expectancy is seven years less for those with fewer than 12 years of education as compared to a person with a college education (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010). Finally, employment has significant influence on health. Hergenrather and colleagues (2015) reviewed 22 longitudinal studies examining the relationship between employment status and physical health and found that unemployment and job loss were associated with poorer physical health.

Given the multiple and intersecting influences on health, researchers continue to debate the specific mechanisms by which social group membership and location of residence contribute to poor health. Additionally, interpretations of health and the meanings attributed to poor health and/or disability vary according to culture and create nuances that must be understood in order for healthcare practice and policy to succeed in reducing health disparities. For example, when investigating the illness experiences of

African Americans living with coronary heart disease (CHD), Dubbin, McLemore, & Shim (2017) identified that CHD was perceived as a product of ongoing racial and socio-structural dynamics through which health burdens are created, sustained, and reproduced. Harrison, Angel, and Mann (2008) identified that for Mexican-American women aging with childhood-onset disabilities, culture situated in specific geographic locales influenced the meaning of health and gender as well as the experience of disability- and ethnic-related discrimination. Putnam and colleagues (2003) explored the meaning of health to people with long-term disabilities (i.e., diagnostic conditions including cerebral palsy, polio, multiple sclerosis, amputation, and spinal cord injury). Participants identified the ability "to function and to do what they wanted to do" as a primary characteristic of health (Putnam et al., 2003, p. 38). Similarly, Harrison and colleagues (2010) identified that women aging with disabilities perceived health as "being able to do" (p. 825). Furthermore, exploring the meaning of health among rural people, Long and Weinert (1989) found that rural-dwellers equate health with the ability to work and to function in their daily activities.

This researcher proposes that the above-cited social and cultural influences, interpretations, and cultural meanings may not be adequately captured by clinical definitions of health as a specific physical or psychological state. Instead, it is posited that widening the scope of health policy and practice to consider an individual's well-being may facilitate the recognition of social, cultural, or environmental influences on an individual's health status. Further, this researcher speculates that this broader scope could position health as an important determinant of well-being thereby prompting important conversations between healthcare providers and patients regarding why it is that patients seek healthcare—that is, for what reason does a person pursue health? The next section will provide an overview of well-being including contemporary discussions within the

disability field that have highlighted potential drawbacks of considering well-being as a policy goal.

WHAT IS WELL-BEING?

Well-being is considered to be a subjective experience based on the idea that how each person thinks and feels about his or her life is important (Diener & Suh, 2000). The fuzzy nature of this concept has resulted in a deep skepticism regarding a transition to assessing policy outcomes in terms of well-being instead of more traditional indicators such as income or access to substantive goods. Specifically, Bickenbach (2014) related that disability researchers worry that analysis of well-being might lead researchers to focus on internal factors (such as coping mechanisms or personality styles) to a degree that overlooks the impact of external social factors (such as discrimination and oppression) or environmental barriers (such as inaccessible offices or sidewalks) on the daily lives of individuals. That is, a focus on well-being could inadvertently reinforce the view that people are solitary beings unaffected by the outside world. Thus, one can see that without careful consideration, one potential consequence of a scholarly focus on well-being would be to redefine "public issues as the private problem of the individual" (Furedi, 2004, p. 25).

Another area of concern is that until recently, most philosophical discussions of well-being treated disability as a straightforward condition that lowered the overall quality of one's life (Wasserman, Asch, Blustein, & Putnam, 2016). As scholars including Vehmas and Watson (2014) and Barnes (2014) have argued, it is not at all clear that the relationship between disability and well-being is so straightforward. Indeed, with appropriate environmental and social supports, many people with disabilities report quality of life to be as high or higher than those without disabilities (e.g., Albrecht &

Devlieger, 1999; Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfstom, 2012; Dunn, Uswatte, Elliott, 2009). Further, it has been argued that a conceptualization of impairment as an inherent reduction of individual well-being is both insensitive and factually incorrect in many instances, particularly in those for whom an impairment has been thoroughly internalized and forms part of one's identity (Bickenbach, Felder, & Schmitz, 2014). Thus, there is strong evidence demonstrating that impairment does not necessarily prevent one from living a good and valuable life, but this does not negate the fact that many impairments are painful and choice limiting. However, with environmental modifications and adaptations, many people are able to overcome functional limitations and to choose from among a sufficiently wide array of life plans that it could be considered a mistake to believe that their well-being had been lowered much or at all by their impairments (Brock, 1993; Reinders, 2014). Therefore, to prevent a shift from policies that consider the needed access to external goods or required environmental modifications to encouraging individuals to take more responsibility for their own happiness, researchers should clearly define what is meant when calling for improved well-being as a policy outcome.

WELL-BEING AS THE CAPABILITY TO *DO* AND TO *BE*

The capabilities approach is a normative framework used in social justice research that provides an alternative conceptualization of well-being in terms of what an individual can do and be in his or her life (Sen, 1985). This framework has been widely used in the fields of human development and economics (e.g., Lorgelly, 2015; Mitchell, Roberts, Barton, & Coast, 2015; Muffels & Headey, 2011) disability studies (e.g., Burchardt, 2004; Mitra, 2006; Venkatapuram, 2014) and education (Terzi, 2005; Walker, 2012). It is also gaining traction as a useful framework for analyzing health inequities

(Abel & Frohlich, 2012; Weaver, Lemonde, Payman, & Goodman, 2014), but it has not yet been widely used within the nursing discipline. Thus, this dissertation seeks to establish the capabilities approach as a useful framework for nursing practice and research in light of professional codes of ethics, contemporary practice models that include social determinants of health, and health disparities research (Thompson, 2014).

Within this dissertation, well-being is defined according to the capabilities approach as an individual's realistic opportunities for pursuing and achieving those things he or she has reason to value, and these realistic opportunities are facilitated or hindered by social and environmental circumstances (Sen, 1985). The term *functionings* is used to represent the things that an individual succeeds in being or doing. According to the capabilities approach, a person's well-being is an index of his or her functionings, and these functionings emerge from his or her *capability set* (Sen, 1985). The capability set, in turn, is defined as an individual's opportunities for achieving things he or she has reason to value and encompasses the range and variety of choices available to that person. Importantly, the capabilities approach values the capability set as the outcome of interest as it allows a consideration of the real opportunities available to a person and of human agency.

A capabilities approach to social justice makes explicit that equal distribution of resources (such as income) will not result in equality of freedom to pursue well-being because people have differing needs for resources. Likewise, measuring an individual's subjective feelings about his or her current state is not sufficient to ensure that a person has the resources needed to overcome his or her functional limitations in order to choose between valuable functionings. Further, valued lives are those that people have reason to value. Because a capabilities approach incorporates objective evaluations of a person's real opportunities and allows space for an individual's subjective evaluation of the

meaningfulness or value of those opportunities, it is useful when studying well-being among adults with disabilities. Indeed, prior evidence supports the notion that greater purpose in life is associated with less physical decline among people aging with disabilities (Harrison & Stuifbergen, 2006). Thus, a capabilities approach to collaboration with patients can facilitate identification of personally-meaningful goals as well as social and environmental factors that may conspire to prevent an individual from achieving those goals.

RESEARCH QUESTIONS

It is evident that understanding a person's sociocultural environment is necessary in order to identify the unique social processes that contribute to (or detract from) well-being and thereby develop appropriately tailored practice and policy. However, gaps in our understanding of mechanisms by which factors in the sociocultural environment influence health and well-being remain. As outlined above, we know that sociocultural factors influence well-being among adults with disabilities, but evidence regarding *how* these factors contribute to disparities in well-being remains inconclusive. Further, it is unclear how these factors influence well-being among adults with disabilities in rural populations. Therefore, the following research questions were posed:

1. How does the capabilities approach compare with the ICF in terms of these models' ability to accommodate the diverse experiences and needs of people with disabilities?
2. What are the structural determinants that influence disparities in health and well-being between African-American veterans and their non-Hispanic white counterparts with osteoarthritis?

3. How do working-age adults with disabilities who live in rural communities in Texas define and pursue well-being, and how does the rural sociocultural environment influence both their definition of and their ability to pursue well-being?

PHILOSOPHICAL PERSPECTIVE

This dissertation relies upon a social constructionist perspective situated within a capabilities approach to investigate factors that influence health and well-being. This perspective emphasizes the cultural and historical aspects of phenomena and how meanings of phenomena develop through interaction in a social context (Berger & Luckman, 1966). Through this lens, the cultural and social systems that influence the meaning and experience of health, well-being, and social disadvantage can be examined. Understanding and appreciating the cultural meanings of health, well-being, and disability as well as the subsequent social responses is critical to the ability of nurses to provide holistic care and to confront social and cultural environments that frequently bestow negative meanings to disability (Conrad & Barker, 2010).

DEFINITIONS

- **Capital** has three distinct forms: economic, social, and cultural. Economic capital is money and material assets; social capital refers to resources that can be mobilized via social relationships; cultural capital refers to an individual's resources for action. While distinct, the three forms of capital are interrelated (Bourdieu, 1986).

- **Capability** is the range and variety of choices available to a person. Within the capabilities approach, the capability set represents the freedom of an individual to pursue well-being (Sen, 1985).
- **Conversion factors** within the capabilities approach are individual characteristics, social context, and environmental circumstances which influence the ability of an individual to pursue well-being (Sen, 1992).
- **Culture** consists of the values the members of a given group hold and the norms they follow (Giddens, 1989).
- **Disability** is an umbrella term for impairments, activity limitations, and participation restrictions. It denotes the negative aspects of the interaction between a person's health condition(s) and that individual's contextual factors (environmental and personal factors) (WHO, 2001, p. 8).
- **Discrimination** refers to the process by which a member or members of a socially defined group are treated differently or unfairly because of membership in that group (Kreiger, 2001).
- **Functionings** represent the well-being achievement of a person according to the capabilities approach. Functionings are what a person is or does (Sen, 1985).
- **Health equity** is the absence of systematic disparities in health between social groups who have different levels of underlying social advantage/disadvantage (Braveman & Gruskin, 2003).
- **Health disparities** are potentially avoidable differences in health that adversely affect socially disadvantaged groups and groups that have experienced discrimination or social exclusion (Braveman, et al., 2011).

- **Health inequities** are differences in health that are avoidable, unnecessary, unfair, and unjust (Whitehead, 1992).
- **Grounded theory** is a research design in which the researcher derives a general, abstract theory of a process, action, or interaction grounded in the views of the participants. This research method involves using multiple stages of data collection and the refinement and interrelationship of categories of data (Charmaz, 2006).
- **Social advantage** refers to the attributes that define how people are grouped into social hierarchies. In the United States, these are wealth, power, and/or prestige (Braveman & Gruskin, 2003).
- **Social disadvantage** is the unfavorable social, economic, or political conditions some groups of people systematically experience based on their relative position in social hierarchies (Braveman, et al., 2011).
- **Social justice** broadly refers to action taken by societal actors that are intended to create genuine equality, respect, and fairness among peoples (Reimer-Kirkham & Browne, 2006).
- **Well-being** is defined according to the capabilities approach as an individual's realistic opportunities for pursuing and achieving those things he or she has reason to value, and these realistic opportunities are facilitated or hindered by social and environmental circumstances (Sen, 1985).

ASSUMPTIONS

- Differences in health between social groups are constructed to be fair (or not) based on notions of deservingness, choice, vulnerability, cultural context, and social status (Walker, Rivkin-Fish, & Buchbinder, 2016).
- Political action is shaped and controlled by the language that gives it meaning (Fischer, 2003).
- Health inequities are a negative consequence of social, cultural and political neglect (Harrison, 2017).
- Study participants freely chose to share their experiences with the researcher.
- Study participants had reflected on their life experiences and their rural environment in order to interpret their current life situation and understanding of well-being.
- The researcher's background, values, personal and professional experience, and interests influenced the interpretation of the collected data.

CHAPTER TWO

The purpose of chapter two was to compare the ICF with the capabilities approach in order to discern these models' ability to accommodate the diverse experiences and needs of people with disabilities. Results of this investigation are presented in an issue brief in order to clearly position disparities in health and well-being experienced by adults with disabilities as a matter of equity and social justice. The issue brief incorporates extant literature regarding the ICF and the capabilities approach with findings from this dissertation in order to critically analyze the systemic and cultural

factors that have influenced policy related to the well-being of adults with disabilities. The issue brief concludes with implications of incorporating a social constructionist perspective with a capabilities approach (Sen, 1985) for disability-related practice, research, and policymaking.

CHAPTER THREE

Chapter three is a critical analysis of data from the Veterans Healthcare Administration (VHA). The purpose of this analysis was to document and provide a theoretical explanation for structural determinants of racial disparities in health and well-being. Access to healthcare is an important determinant of health, especially in the context of disability. However, it is clear that access to healthcare alone cannot solve the problem of disparate levels of health experienced by adults with disabilities. This is especially evident when considering disparities experienced by veterans who access healthcare via the VHA. The VHA is intended to provide care to all eligible veterans regardless of social group status, yet veterans who access healthcare via the VHA experience disparities in health based upon race (Peterson, McCleery, & Waldrip, 2015; Saha et al., 2008). The existing literature reveals patient-, provider-, and system-level factors that contribute to racial disparities in health among veterans using the VHA for healthcare. However, the literature stops short of examining underlying reasons for these factors. Thus, chapter three offered a theoretical explanation of the social, cultural, and structural origins of the disparities. Racial disparities in health among veterans with potentially disabling conditions, after controlling for socioeconomic status and access to health care, underscore the importance of addressing nonclinical determinants of health—factors that are not always considered part of the health care system's domain of practice.

CHAPTER FOUR

Chapter four presents a constructivist grounded theory study, the purpose of which was to build a substantive theory to explain how adults with disabilities living in rural counties in Texas define and pursue well-being. Findings from the critical analysis of racial disparities in the VHA reinforced the assumptions that health should be viewed as a means to the end of well-being and, therefore, that myriad and complex factors beyond the traditional healthcare system influence both health and well-being. This study stemmed from these assumptions and from the significant gap in knowledge related to the well-being of working-age adults living with disability in rural America.

The prevalence of disabilities—defined according to the questions in the American Community Survey (See Table 1)—is higher in rural than in urban counties (16.5% vs. 13.4%) (Seekins & Greiman, 2014), and rural areas across the U.S. have a disproportionately high representation of individuals from sociodemographic groups at high risk of poor health outcomes: those with low income, low educational attainment, and advanced age (Meit, et al., 2014). Despite the documented disparities in disability and socioeconomic status between urban and rural areas, we know very little about the experience of living with a disability in rural America. This is problematic given the well-documented influence that social and environmental factors have on health outcomes and well-being for people with disabilities (e.g., Carmona, Giannini, Bergmark, & Cabe, 2010; Drum, 2014; Harrison, Umberson, Lin, & Cheng, 2010). Indeed, the same impairment, in a different social context, can have drastically different consequences for individual lives (Vehmas & Shakespeare, 2014). The goal of study two, therefore, was to build a substantive theory to explain how adults with disabilities living in rural counties in Texas define and pursue well-being.

CHAPTER SUMMARY

In summary, health disparities are pervasive in the United States, and three of the greatest risk factors for poor health outcomes are race, rural residence, and disability. Individuals in these groups experience significant and persistent poor health outcomes and social disadvantages. Such disadvantages contradict ethical principles such as respect for equal moral worth of all and important social values such as non-discrimination. The purpose of this dissertation, therefore, was to explore race, disability, rural culture, and disparities in health and well-being using a social justice lens. Ultimately, a better understanding of the relationship between these phenomena can help to clarify the proper role and scope of policy, to better explicate the theories of well-being that are developed, and to reveal judgments that are made about human lives on a regular basis—judgments that, in turn, shape policy development (Wasserman, Asch, Blustein, & Putnam, 2016). The results of this work can be used to inform practice and policymaking and contribute to culturally relevant health care treatment and policy solutions.

Chapter 2. The Social Construction of Disability and the Capabilities Approach: Implications for Nursing

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Targeted Journal: *Nursing Forum,* Abstract 150-250 words

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ABSTRACT

Eliminating health disparities and achieving health equity are important public policy goals in the United States. More attention is beginning to be directed towards the disparities in health and well-being experienced by many people with disabilities, but structural injustices in the form of social and environmental barriers remain. This issue brief proposes that incorporating Amartya Sen's capabilities approach into disability-related nursing practice and research has the potential to illuminate intersecting factors that influence health and well-being, thereby facilitating a broader embrace of interdependence as a natural state of being that is not unique to people with disabilities. The purpose of this issue brief is therefore twofold. First, it positions disparities in health and well-being experienced by people with disabilities as matters of fairness and social justice that require an analytical framework capable of providing a nuanced understanding of the intersecting influences on health and well-being. Second, it provides suggestions for structuring nursing practice and research according to the capabilities approach. Ultimately, it is argued that ensuring that everyone has equitable opportunities to participate in chosen aspects of life to the best of their abilities and desires is an important healthcare outcome. A capabilities approach to disability-related nursing practice, research, and policy development can expand the disciplinary gaze to include individual-focused interventions as well as efforts to address the inequitable factors that determine the possibilities and the opportunities available to people with disabilities.

Eliminating health disparities and achieving health equity are important public policy goals in the United States (U.S. Department of Health and Human Services [USDHHS], 2018). Despite some progress towards these goals, significant gaps in health and well-being between population groups remain. Over the past 15 years, people with disabilities have gained more attention as a population that experiences health disparities (USDHHS, 2018). This is significant because the consistently poorer outcomes faced by people living with disabilities have not always been recognized as disparities by those outside of the disability community (Barnes, Mercer, & Shakespeare, 1999; Krahn, Walker, & Correa-de-Araujo, 2015). Instead, differences in health or social status are often attributed to functional impairment or to poor health that preceded disablement. Now that people with disabilities have gained recognition as a health disparity population, disability itself is beginning to be reframed as a demographic indicator instead of merely an outcome to be avoided. Consequently, researchers have increasingly focused attention on the subjective experience of living with a disability as well as the cultural and socially embedded meanings of impairment. Despite these efforts, progress towards eliminating health disparities and achieving health equity for people with disabilities has been slow. Disability continues to be regarded as a deficiency located wholly within the individual body or mind, especially as compared to the "normal" or "ideal" (Arneil, 2009). Thus, the disability component of diverse and individual lives serves as justification—whether explicit or implicit—for the often-poor socioeconomic circumstances and health status of individuals with disabilities (Yee et al., 2018). Individuals with disabilities are therefore often viewed as beyond the scope of distributive and social justice (Riddle, 2014).

Analysis of data from the Behavioral Risk Factor Surveillance System (BRFSS), indicates that over 50 million people live with some type of disabling condition the

United States (See Table 1 for disability measures; Courtney-Long et al., 2015). Considering the significant percentage of the American population who will live with impaired physical or mental capacities at some point in their lives, achieving equity in health and well-being for people with disabilities will be nearly impossible if disability continues to be 'put aside' during discussions of social justice (Rawls, 1971, p. 245). Further, in order to challenge the continued disparities and structural injustices experienced by people with disabilities, it is necessary to understand the sociocultural meanings of disability and to incorporate this understanding into policy and clinical practice.

The purpose of this issue brief is twofold. First, it presents disparities in health and well-being experienced by people with disabilities as matters of equity and social justice requiring a framework that can consider the subjective experiences of people with disabilities and provide a nuanced understanding of intersecting influences on their health and well-being. These influences include factors stemming from both inadequate healthcare received by people with disabilities as well as from the sociocultural environment outside of the healthcare system. Second, it provides suggestions for structuring nursing practice and research for the purpose of combatting continued structural injustices facing people with disabilities in the U.S. This twofold purpose will be accomplished by presenting an overview of difficulties associated with defining and measuring disability and of social and health indicators regarding disparities experienced by people with disabilities. The brief will then highlight the shortcomings of approaches that rely solely on objective measures of social participation and well-being to design disability-related policy and programs, and it will conclude with a proposal that a capabilities approach (Sen, 1992) is a framework well-suited to guide nurses engaged in

practice, research, and policy development in their efforts to advance health equity for people with disabilities.

DEFINING DISABILITY

There is no universally agreed-upon definition of disability. The ongoing debate about this term results largely from the diversity of experience of disability. That is, disability may be lifelong, resulting from an event at or around birth, or it may occur suddenly as the result of an acute disease (such as meningitis) or injury (such as a fall from a ladder). Disability can also result from chronic conditions that affect physical or cognitive function, such as multiple sclerosis, osteoarthritis, diabetes, or Parkinson's Disease. Moreover, disability severity can vary from minor difficulties to major effects on a person's life and major barriers encountered (Kostanjsek et al., 2013). Thus, disability is multidimensional and contextual, resulting in a number of different approaches to its definition.

For much of the past 40 years, disability has been defined from a medical model that construes disability as an individual biological deficiency, a social approach, or an approach that combines aspects of each. It is critical to examine the foundations of these different approaches in order to understand why certain policies and programs have developed as they have. Further, the approach taken to defining and understanding disability affects how an examination of justice and disability is pursued. Without understanding how—or whether—disadvantage results from disability, we risk formulating a conception of social justice that fails to take into account the multiple forms and sources of disadvantage that could be experienced by people with disabilities (Riddle, 2014). We also risk privileging an objective perspective that may be easier to quantify but serves to diminish the importance of the individual's subjective experiences

of impairment and disability. Indeed, understanding the cultural meanings of disability can yield insight into how disability is experienced by the individual within a sociocultural context as well as how policies concerning disability are constructed (Conrad & Barker, 2010; Harrison, 2006). Cultural meanings of disability can also illuminate how individuals form social judgments and assumptions about disability that indirectly influence policy formation. The next section provides a brief overview of three commonly-used disability models: the medical model; the social model; and the *International Classification of Functioning, Disability, and Health* (ICF; World Health Organization [WHO], 2001).

Medical Model

Along with the professionalization of medicine in the late 19th century came the ability for physicians to diagnose biological causes of impairment. This new diagnostic capability gave rise to the notion that disability is the result of individual differences of biology stemming from illness, injury, or some other health condition (Stone, 1984). Thus, the medical model of disability is based upon two main assumptions: 1) individuals should strive, largely through their own efforts and guided by healthcare professionals, to overcome disabilities, and 2) healthcare professionals know what is best for patients (Iezzoni & Freedman, 2008). It is widely agreed that the medical model of disability has dominated medical and therapeutic research and practice (e.g., Barnes, Mercer, & Shakespeare, 1999; Priestley, 2003). As such, the traditional view within healthcare has been to assume that someone with an impairment would find it difficult to perform so-called normal activities and to fulfill expected social roles. Policies and services based upon a medical model of disability have, therefore, aimed at providing medical treatment and rehabilitation to cure or to help the individual adjust to his or her situation

(Finkelstein, 1993). Medical care is viewed as the main issue, and modifying healthcare policy to expand access to treatment is perceived as the best political response (WHO, 2001).

The significant criticisms of the medical model of disability are that it characterizes people with disability as being defined by their disability, inferior to people without disabilities, incapable of leading fulfilling lives, dependent, and in poor health (Sunderland, Catalano, & Kendall, 2009). These negative representations undermine the individuality, unique experiences, and agency of people with disabilities by producing and reinforcing stereotypes. Further, by focusing the problem of disability as something that arises from within the individual, the medical model places responsibility for overcoming barriers chiefly upon the individual, and society is not held accountable for its role in creating and maintaining disabling environments.

Social Model of Disability

By the 1970s, proponents of a new social model of disability began to confront traditional medicalized notions of disability (Iezzoni & Freedman, 2008). The social model of disability posits that disability is not an individual issue. Rather, disability becomes a problem because of environments that fail to accommodate persons with impairments and because of negative and stigmatizing attitudes held by people without disabilities (Oliver, 1996). This conceptualization holds that disability is not a natural result of an impairment, but is something imposed on top of impairment by the systematic isolation of people with disabilities and the resulting exclusion from full participation in society. Social model proponents contend that disability is a complex collection of conditions, many of which are created or intensified by the social environment. The issue, therefore, is attitudinal and ideological as well as physical. As

such, social and environmental change are both required in order to promote better health outcomes and equity for people with disabilities. In other words, disability is a political issue and a question of human rights, not an exclusively medical issue (WHO, 2001).

The influence that the social model of disability has had on the lives of people with disabilities over the past four decades is difficult to overstate. It has been hailed for its usefulness in raising the awareness of the oppression of people with disabilities, a critical first step towards action (Peters, Gabel, & Symeonidou, 2009). However, many people with disabilities have criticized this model's bracketing of impairment as entirely separate from disability as an inaccurate account of their lived experiences, arguing that the model fails to acknowledge how impairment is part of their daily personal lives (Shakespeare & Watson, 2001). Impairments often have very tangible effects on people's well-being; it is argued, however, that seeing impairments as acceptable forms of human diversity is not the same as seeing them as neutral or insignificant (Vehmas & Watson, 2014). Recognizing the salience of impairment in daily life runs contrary to the social model of disability, and this lack of recognition is regarded as the model's greatest limitation.

International Classification of Functioning, Disability, and Health.

Recognizing the need to link competing perspectives of disability into a coherent view of health, in 2001, the World Health Organization integrated aspects of the individual/medical and the social models of disability into the *International Classification of Functioning, Disability, and Health* (WHO, 2001). The ICF was intended to provide a standard language and conceptual basis for the definition and measurement of health and disability. The ICF is thus a combined biopsychosocial approach that holds that disability is the effect of an individual with an impairment

interacting with some larger attitudinal, social, or environmental phenomena (Drum, 2014). The ICF introduced the concept of participation, defined as "involvement in a life situation" and participation restrictions are defined as "problems an individual may experience in involvement in life situations" (WHO, 2001, p. 10). Despite the conceptual ambiguity of these terms, the evolution from measuring a person's handicap to measuring participation was instrumental in the burgeoning movement to widen the gaze of policymakers, researchers, and practitioners to consider participation in daily and social life as an explicit component of health (Iezzoni & Freedman, 2008). This shift reinforced the notion that disability is not synonymous with poor health.

The possibility of an interdisciplinary and shared understanding of disability that incorporates social and environmental factors has been an important contribution of the ICF. Indeed, the ICF has been a useful tool for health outcomes research and population surveys, and it has provided an organizational basis for social policy (Imrie, 2004). However, the ICF has been subjected to several critiques. Chief among them is that the ICF specifically excludes subjective experiences of participation and ignores the reality that what people are observed to do is not necessarily what they wish or choose to do (Hammel et al., 2008). Indeed, the ICF is argued to err by assuming that when a person with a disability is seen to participate in society in some way, it is because he or she has freely chosen to do so. That is, the ICF attributes to people with disabilities a level of autonomy and personal agency that they may not actually experience or perceive due to socioeconomic constraints or attitudinal and environmental barriers. Thus, the ICF fails to consider that in order to truly improve a person's health and well-being, participation should be consistent with the person's choices about how they want to live their life; that participation is a subjective experience given meaning through choice; and that choices are facilitated or constrained through social, economic, and cultural contexts.

While the ICF represented a significant advancement towards understanding disability as resulting from the interaction of a person with an impairment and some larger phenomena, it falls short of being able to adequately conceptualize a person with a disability as someone who lives life interacting with others, with environments, with societal expectations about roles, and with large-scale political and economic systems (Drum, 2014). Indeed, insights from a long line of research regarding the cultural meanings of disability (e.g., Harrison, 2011; Harrison et al., 2013; Vehmas & Shakespeare, 2014) suggest the importance of shifting from a biomedical emphasis and towards changing the social and cultural contexts that frequently associate disability with negative meanings. Thus, a more comprehensive mechanism for considering the contexts of lived experience is still needed. This is a critical point to which I will return, but the next section provides an overview of a few selected disparities experienced by people with disabilities. This overview is intended to illuminate some of the contextually-situated lived experiences that current models of disability are unable to adequately conceptualize.

DISABILITY AND DISPARITIES

Incorporating measures of disability as a baseline demographic characteristic has allowed researchers to begin to deconstruct the traditional perspective that disability is equivalent to poor health. People with disabilities do, however, frequently experience lower levels of health than do people without disabilities. For example, state and national studies using data from the BRFSS and from the Medical Expenditures Panel Survey (MEPS) have found that individuals with disabilities (See Table 1) report lower health status than do those without disabilities (Havercamp, Scandlin, & Roth, 2004; Pharr & Bungum, 2012; Reichard, Stolzle, & Fox, 2011). Also using data from the MEPS,

Reichard, Stolzle, and Fox (2011) and Wei, Findley, and Sambarmoorthi (2006) found that people with disabilities exhibit higher rates of multiple chronic illnesses as compared to the general population. Further, Carroll and colleagues (2014) used data from the National Health Interview Survey (NHIS) and found that adults with disabilities are three times more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities. While it is true that disability may result from chronic illness such as stroke or diabetes, research has also demonstrated that people with lifelong disabilities experience health disparities. For example, Dixon-Ibarra and Horner-Johnson (2014) used NHIS data and identified that after controlling for age, sex, race/ethnicity, marital status, and working status, people with lifelong disabilities had significantly higher odds of coronary heart disease, cancer, diabetes, and hypertension. This evidence suggests that health disparities experienced by adults with disabilities cannot be solely attributed to underlying medical diagnoses or conditions.

One contributing factor to lower levels of poor health is inadequate health care received by people with disabilities. For example, adults with disabilities are far less likely to receive important preventive screenings for cancer including mammograms and prostate checks or to have regular dental check-ups (Courtney-Long, Armour, Frammartino, & Miller, 2011; Merten, Pomeranz, King, Moorhouse, & Wynn, 2014; Schootman & Jeffe, 2003). Further, women of child-bearing age with mobility limitations have been found to be 70% less likely to be asked about contraception during routine medical office visits (Iezzoni, McCarthy, Davis, & Siebens, 2000). This disparity increases their risk for a host of health complications and underscores a widespread negative stereotype among clinicians that women with physical difficulties are not sexually active (Becker, Stuifbergen, & Tinkle, 1997). A wealth of evidence exists documenting the persistence of negative and stigmatizing attitudes towards people with

physical disabilities on the part of healthcare professionals across the healthcare spectrum (e.g., Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016; Rashid-Kandvani, Nicolau, & Bedos, 2015). People with disabilities also continue to face inaccessible medical offices and examination equipment as well as office policies that prevent them from receiving adequate and accessible healthcare communications (Yee & Breslin, 2010). These shortcomings of the healthcare system in the U.S. can lead to inadequate examinations, missed diagnoses, and worsening health for people with disabilities—manifested as the health disparities cited above. However, evidence also indicates that health disparities originate from social and structural inequities outside of the healthcare system (Thurman & Harrison, 2017). Thus, a full understanding of health disparities requires a critical examination of societal conditions such as income and education.

Income has a well-established association with health (Braveman, Egerter, & Williams, 2011), with research indicating that U.S. adults living in poverty are more than five times as likely to report being in fair or poor health as adults with incomes at least four times the federal poverty level (Braveman & Egerter, 2008). Other research estimates that living on incomes of less than 200% of the federal poverty level has a larger effect on health outcomes and mortality than tobacco use and obesity (Muennig, Fiscella, Tancredi, & Franks, 2010). Education is another important determinant of health. Research indicates that adults without a high school diploma or GED are three times as likely as those with at least some college education to die before age 65 (Heron et al., 2009), and life expectancy is seven years less for those with fewer than 12 years of education as compared to a person with a college education (Braveman, Cubbin, Egerter, Williams, & Pamuk, 2010). Using data from the NHIS, Stevens and colleagues (2016) found that people with disabilities were significantly more likely to live in poverty, to have less than a high school education, and to be unemployed. Thus, it seems evident

that for people with various disabilities, opportunities to achieve optimal health and well-being continue to be restricted. Indeed, exclusion from important social roles continues to serve as a formidable barrier for people with disabilities despite 27 years of protection under the Americans with Disabilities Act (ADA).

The ADA was passed and signed into law by President George H.W. Bush in 1990. This was rightfully hailed as a watershed moment for the disability community, as it was the first federal legislation intended to prevent discrimination against people with disabilities in all aspects of society. This comprehensive civil rights legislation and the provision of needed supports and services have been critical for enabling adults with disabilities to live independently in their communities and to participate in valued life activities. Implicit in the ADA was an attempt to reframe independence—a core American value—as *interdependence* by acknowledging that the need for social support to choose and follow a course of action is not synonymous with dependence or poor health (Harrison, 2002). However, structural inequalities facing people with disabilities—that is, "a set of reproduced social processes that reinforce one another to enable or constrain individual actions in many ways" (Young, 2001, p. 2)— have not yet been fully dismantled in American society. This can be at least partially attributed to the fact that the ADA did not "represent a fundamental shift in the cultural meaning of disability" (Conrad & Barker, 2010, p. S71). It is suggested, therefore, that a missing piece in the continued struggle against structural injustice may be a social justice framework that is inclusive of people with disabilities and makes an explicit commitment to promoting equity. That is, this framework should be able to accommodate cultural meanings and subjective experiences of individuals with disabilities living in specific social contexts. The next section will further explain why a foundational framework inclusive of people

with disabilities is needed and define the concepts of distributional and social justice, which are essential components of such a framework.

DISABILITY AND SOCIAL JUSTICE

Distributive justice concerns the nature of how the benefits and burdens of a society are distributed across members of that society. The laws, institutions, policies, and values governing a society result in different distributions, and debates about which frameworks and/or resulting distributions are morally preferable constitute the topic of distributive justice (Lamont & Favor, 2017). Most frequently, distributive justice frameworks are underpinned by principles of utilitarianism or egalitarianism. Utilitarianism seeks to maximize welfare, and distributive justice theories based in utilitarianism seek to answer the questions of what counts as welfare and how to maximize the welfare of the greatest number of people (Stein, 2006). In contrast, egalitarian theories of distributive justice advocate for equality of some sort and attempt to tell us how to help those who are in some way disadvantaged (Stein, 2006). That is, for egalitarian theorists, the top priority (given limited resources and capacity) is not to help the greatest number of people but to focus efforts on those considered to be most disadvantaged according to some pre-determined metric.

Regardless of the philosophical bent, people with disabilities have not historically been considered part of the purview of distributive justice. Instead, in Western political thought, people are conceived as belonging to one of two groups: those who are governed by the principle of justice and those who are governed by the principle of charity (Arneil, 2009). John Locke originated this distinction by proclaiming that "*Justice* gives every man a Title to the product of his honest industry… so *Charity* gives every man a Title to so much out of another's Plenty, as will keep him from extreme want, where he has no

means to subsist otherwise" (Locke, 1988). Phrased in this way, we see the beginning of people with disabilities being set aside during discussions of distributive justice, as well as the branding of an image of people with disabilities as dependent on the good will of other citizens (Ball, 2000).

Social justice, in contrast, is concerned with identifying and classifying different aspects of individual lives with which society should be concerned. These include: the extent to which individuals' basic needs are met, the resources available to them relative to others, their opportunities, their status, and their degree of recognition (Burchardt & Craig, 2008). Thus, we can see that social justice should not be reduced to distributive justice. For people with disabilities who have been largely "set aside" during discussions of distributive justice, this distinction is even more critical. An adequate social justice framework can, therefore, direct attention to the health and social disparities experienced by people with disabilities while simultaneously allowing individuals to exercise their will, live healthy lives, and achieve their full potential (Chinn & Kramer, 2011). Critical to the development of such a framework, however, is attention to the subjective experiences of individuals with disabilities within the sociocultural environments in which they live.

The wealth of research regarding the social construction and cultural meanings of disability has allowed intimate knowledge regarding how individuals make sense of illness or impairment in the context of their personal relationships, social context, employment status, and faith beliefs. For example, early work by Strauss and Glaser (1975) investigating the social construction of illness revealed that the patient experience is not the same as the illness experience; most people with illnesses do not spend a significant amount of time in the patient role (Conrad & Barker, 2010). Research has also illuminated the meaning of aging with disability and the cultural expectations regarding

social and gender roles in the United States (Harrison, 2006; Harrison, Angel, & Mann, 2008). More recent evidence comes from a critical analysis of racial disparities within the Veterans Healthcare Administration. Specifically, that work demonstrated that social meanings of disability and health care preferences resulted in differential willingness and ability to pursue surgical intervention for a potentially disabling condition (Thurman & Harrison, 2017). Cultural meanings of disability also vary depending upon geography; recent work has revealed the importance of maintaining group membership within the rural environment for adults with disabilities.

The above comprise only a few examples of how a constructionist approach to health and disability takes the subjective experience seriously in order to examine the personal and social meanings of illness or disability and determine how impairment is managed within particular social contexts. Critically, this line of research has revealed the importance of human agency to the experience of disability (Conrad & Barker, 2010): one's capacity to adapt to the changing body within the sociocultural environment is critical to life with a disability (Harrison, 2006). Thus, it is argued that effective nursing care and policy would be enhanced by a consideration and appreciation of the cultural meanings and subsequent behavioral consequences of disability or chronic illness. A capabilities approach to disability has the potential to provide this much-needed expansive view.

A Capabilities Approach to Disability

The capabilities approach, originally developed by Amartya Sen in the 1980s, is a "broad normative framework for the evaluation and assessment of individual well-being and social arrangements, the design of policies, and proposals about social change in society" (Robeyns, 2005, p. 94). The central principle of the capabilities approach is

attention to what people can do or be—termed *capabilities*—combined with recognition of the diversity among people in society and the unique needs that may arise from such diversity (Robeyns, 2005). This framework emphasizes the fact that different people have different needs depending upon personal characteristics (such as age, gender, or impairment) and upon external factors (such as availability of resources and environmental barriers). Thus, the capabilities approach explicitly recognizes that equal distribution of resources (such as income or healthcare) is not sufficient to bring about equity of freedom to pursue well-being.

Like the ICF, the capabilities approach suggests that we must consider the interface between the individual and his or her social and environmental context in assessing which characteristics may lead impairment to turn into participation restrictions and how those restrictions, in turn, impact capabilities (Terzi, 2005). However, the capabilities approach differs from the ICF in that it explicitly calls for attention to be paid to the diversity in human experience: race, poverty, impairment, and age, for example, all combine to create unique influences on a person's life. Further, the capabilities approach holds human agency as a principal concern and "gives a central role to a person's actual ability to do the different things that she values doing" (Sen, 2009, p. 253). Importantly, the capabilities approach does not make the claim that ability is limited to *intrinsic* ability. Rather, ability is represented by a person's *capability set*, which is synonymous with the individual's substantive freedom to be or to do something. This freedom may be constrained or facilitated by the social, economic, and physical environment in addition to or instead of intrinsic ability (Burchardt, 2004). In other words, a capabilities approach can further facilitate an embrace of interdependence by recognizing that the need for assistance and social support to overcome environmental barriers is not equivalent to dependence or poor health (Harrison, 2002). Indeed, interdependence is a

characteristic of all human life, not a deviation associated only with disability (Cardol, de Jong, & Ward, 2002). The embrace of interdependence, in turn, can center a relational autonomy that recognizes that capabilities are developed and exercised only in relationship with others—regardless of disability (Entwistle & Watt, 2013).

A capabilities approach also holds that valued lives are those that people have reason to value. Sen (1992) argues that "attention should be given to individual conceptions of well-being, and to their interplay with political, social, and cultural settings, thus, ultimately, with conditions that may influence choice and reasoning" (p. 206). Therefore, the capabilities approach goes beyond the ICF classification system both by incorporating objective evaluations of a person's real opportunities for participation and by allowing space for an individual's subjective evaluation of the meaningfulness or value of those opportunities. As such, this approach facilitates the examination of opportunity structures and the extent to which an individual can exercise personal agency in choosing between valuable activities.

When using the capabilities approach, disability can be analyzed as capability deprivations that result from a combination of different factors (Mitra, 2006). Sen provides several examples of disability and its demands on justice throughout his writings. He pays particular attention to the different conversion of resources into valued outcomes experienced by people with disabilities (Terzi, 2015). For example, if a person's impairment prevents him from walking, ensuring that he has a wheelchair for mobility and that his environment is accessible via wheelchair means that despite his inability to walk, his capability set is not necessarily reduced because he maintains the ability to navigate his environment. However, wheelchairs are expensive, and ensuring accessible environments is not within the purview of an individual person. Further, if the person has no reason to navigate the environment because of a lack of meaningful

opportunities or has no desire to do so because of social stigma he experiences in the community, his capability set is still reduced, despite his access to appropriate assistive devices. Therefore, justice requires that the added difficulty and costs associated with converting resources into well-being because of disability be considered by relevant stakeholders (Sen, 1999). Depending upon the specific issue under consideration relevant stakeholders will likely be a broad coalition including academic researchers, policymakers, healthcare providers, insurance companies, public health agencies, educators, non-governmental organizations, and/or faith communities. A capabilities approach can facilitate this collaboration. The next section will provide suggestions for introducing a capabilities approach into nursing practice, research, and policy for people with disabilities.

IMPLICATIONS FOR NURSING

According to Conrad and Barker (2010), any policy response to a problem is determined by how the problem is defined in the first place. Therefore, acknowledging the social construction of disability can bring critical awareness to the policy-making process. Understanding cultural meanings regarding the social experience of impairment can facilitate a more equitable distribution of resources and important social goods to people with disabilities. For example, as Harrison (2006) has argued, legislatively-mandated and socially-sanctioned time periods for work and retirement leave many people with disabilities struggling to meet the demands of their work roles and frequently requiring assistance for which they do not qualify based on age or assets. When faced with this realization that the ill-fit between social policy, cultural expectations, and individual ability contributes to significant disparities in health and well-being between people with disabilities and those without, what is the best response on the part of the

nursing discipline? Hammell (2015) asked a similar question of occupational therapists: as healthcare professionals, do we encourage each person with a disability to adapt themselves to their environment and attempt to change each person's body so that it more closely adheres to valued social norms (reflecting a biologically-oriented view of disability)? Or, should we act to directly challenge the myriad barriers stemming from the sociocultural, economic, and political environments that reinforce disability as "deviance" (Goffman, 1963), thereby providing opportunities for some but routinely denying them to others? Clearly, the answers to these questions have implications for the practice of nursing at all levels, and it is argued that the nursing discipline has an important role to play in influencing policy in order to combat structural injustices.

It has been said that nurses are privileged to "practice at the intersection of public policy and personal lives" (Falk-Rafael, 2005, p. 222), and this makes nursing as a discipline ideally situated to challenge disability-related injustices. It is within this context that the capabilities approach can be useful as a guiding framework within the discipline. Indeed, the participatory approach to identifying relevant capabilities promoted by Sen is well-suited to nursing practice and science because of the discipline's commitment to patient-centered practice and the promotion of health and well-being for each patient, family, and community. Nurses at all levels of practice must engage with people with disabilities in order to identify capabilities that are deemed important and relevant given a person's social context and unique personal characteristics.

Regardless of disability, people vary in the kinds of support they need to develop and exercise their capabilities, and the nursing role will vary depending upon individual circumstance. Thus, if we accept the principle that people are all interdependent to varying degrees at different points within any given lifespan, then we can understand disability as a dimension of human diversity across space and time, rather than a tragedy,

deficit, or abnormality (Arneil, 2009). This acceptance of interdependence can also foster recognition that every individual's capabilities are socially shaped and that people have capabilities in various ways and to different extents; this recognition is paramount in order to promote meaningful participation in social life. Meaningful participation, in turn, enables people to experience personal control and social recognition, but meeting these needs largely depends on the availability of opportunities to act and to be known as well as on the value of available activities (Siegrist & Fekete, 2016). Thus, it is not sufficient to simply stand back and give people who have well-developed capability sets space to exercise them. Nurses must also positively enable capabilities by working at the social and environmental levels to facilitate the development of capabilities in people with disabilities for whom capabilities often depend, in large part, on external factors.

Working to cultivate and enable capabilities could entail advocacy at the local, state, or federal levels; intensive case management to secure needed supports and services; and/or collaboration with non-traditional healthcare partners, such as public transportation providers, to ensure accessible transportation options. Cultivating capabilities may also require nurses to work in tandem with local school officials to ensure that children receive the educational and healthcare supports to which they are entitled or to partner with local faith communities to reach potentially vulnerable and socially isolated members who may be in need of health or social services. Collaborating with and recognizing the unique and valuable roles of the interdisciplinary care team including rehabilitation professionals such as occupational and physical therapists, physicians, pharmacists, and social workers will also be necessary. Finally, cultivating capabilities will require continued research investigating the most feasible mechanisms for adapting healthcare interventions to reflect personal abilities within the social and environmental context (Harrison, Umberson, Lin, & Cheng, 2010; Stuifbergen,

Seraphine, Harrison, & Adachi, 2005) and the most relevant competencies for health professional education. Regardless, nurses must take each person's subjective experiences seriously and be attentive and responsive to individuals' unique biographies, social contexts, and important relationships (Entwistle & Watt, 2013).

None of the above suggestions is revolutionary in and of itself. Indeed, the nursing profession has its roots in social justice and population health, and nurses have engaged in these types of activities across the healthcare system for centuries. It is suggested, however, that a guiding framework can assist the discipline as a whole to embrace the responsibility to expand practice to routinely incorporate a consideration of a person's freedom to pursue meaningful activities. It is proposed that using a capabilities approach as this guiding framework can facilitate the interpersonal relationships, professional support, cultural change, and policy solutions that are needed in order to help people of all abilities identify and pursue their own particular interests.

CONCLUSION

For the reasons discussed above, the capabilities approach should be considered for widespread application within nursing research and practice related to disability. The capabilities approach gives explicit attention to the issues of health equity, health inequality, and social arrangements. This is even more critical when considering impairment and the role of social arrangements in creating disability. In 2001, Browne urged nursing scholars to examine whether the theoretical underpinnings of nursing science disrupt or inadvertently help to maintain social inequalities. With an embrace of the capabilities approach, nursing at all levels can move towards a disruption of systems that perpetuate social injustice and the resulting disparities in health and well-being for people with disabilities.

Equitable opportunity for all individuals to participate in chosen aspects of life to the best of their abilities and desires is an important healthcare outcome. It is argued that recognizing the ill-fit between social policy, cultural expectations, and individual ability is a critical step toward ensuring more equitable resource distribution. A capabilities approach can expand the disciplinary gaze to include individual-focused interventions as well as efforts to address the inequitable factors that determine the possibilities and the opportunities available to people with disabilities. With this person-centered and culturally-appropriate approach to policy development and healthcare treatment, people with disabilities can be supported as they enact their human agency to pursue activities and opportunities that provide personal meaning and well-being.

Chapter 3. Social Context and Value Based Care: A Capabilities Approach for Addressing Health Disparities[1]

[1]This manuscript has been previously published. The full citation is:
Thurman, W., & Harrison, T., (2017). Social context and value-based care: a capabilities approach for addressing health disparities. *Policy, Politics, and Nursing Practice, 18*(1), 26-35. This article originated from a class assignment of Whitney Thurman's during the spring 2016 semester. The theoretical argument, empirical analysis, and initial draft of the manuscript are original to that assignment and were completed by Whitney Thurman. Tracie Harrison provided insight into the applicability of the capabilities approach for use as an overarching framework for research and policy development. She was also instrumental in ensuring the overall focus, clarity, and consistency of the article.

ABSTRACT

Racial disparities in health are persistent and pervasive in the United States. Researchers and policymakers have known for decades that access to health care is not sufficient for addressing health disparities because of the socially situated roots of the disparities. We argue that the lack of progress in alleviating health disparities is the result of a lack of overarching framework to guide both policymakers and researchers in their efforts. We propose Amartya Sen's capabilities approach as a normative framework that is expansive enough to address both the social context in which health occurs as well as the quality of health care provide. In this article, we use a subset of veterans receiving care from the Veterans Health Administration to review the theoretical concepts that link social inequalities with health disparities. Next, we provide empirical evidence of disparities in health based on race within the Veterans Health Administration, and we then provide a theoretical explanation for those disparities that exist at a system level. We close with a detailed examination of the applicability of the capabilities approach in addressing health disparities in the United States.

Disparities in health can be categorized based upon a person's race in the United States (e.g., Braveman, Cubbins, Egerter, Williams, & Pamuk, 2010; Williams, 2012). For centuries, race has been used to systematically segregate, marginalize, and stigmatize groups of people; thereby, race has become one of the most significant social categories in the U.S. (American Sociological Association, 2003). Within the U.S. health care system, the results of the aforementioned systematic segregation of people based upon race have manifested as health disparities. The U.S. population can no longer tolerate premature and inequitable levels of morbidity and mortality based upon race.

Albeit, health disparities manifest along socioeconomic gradients; socio-economics do not explain the entirety of health inequity. In other words, not all racial disparities in health are eliminated by controlling for income or education. For example, even though an inverse association between a mother's educational attainment and infant mortality holds true across racial groups, the infant mortality rate for college-educated African American women is more than two and a half times that of college-educated white women (Williams, 2012). The infant mortality rate of African American college graduates is higher than that of white women who did not finish high school (Williams). Other examples, such as those reported in the Veteran's Health Administration (VHA), which provides care to all eligible veterans regardless of race, depict the disparity with upmost clarity. The VHA leadership acknowledges an ongoing struggle to provide the high-quality health care and supportive services to which eligible veterans are entitled (Podolosky, 2014). Yet, veterans who access health care via the VHA experience inequities in health based upon race (e.g., Peterson, McCleery, & Waldrip, 2015; Saha et al., 2008). Racial disparities in health, after controlling for socioeconomic status and access to health care, underscore the importance of addressing factors outside of the

immediate health care system; factors that are not always considered part of the health care system's domain of practice.

The purpose of this article is not to rehash problems already documented in the literature on health disparities due to race. Instead, we offer a framework to move health care beyond the confines of the biological problem-oriented parameters of traditional health care. Using the VHA—chosen because it is a health care system that provides care to veterans with similar socioeconomic backgrounds from all racial groups—as an example, we argue that differing social circumstances result in the lack of capital required to convert health resources into a sense of well-being. We accomplish this in stages. First, we review the capabilities approach and the theoretical concepts that link social inequalities with health disparities. Next, we provide empirical evidence of disparities in health based on race within the VHA, and we then provide a theoretical explanation for those disparities that exist at a system level. We close with a detailed examination of the applicability of the capabilities approach in addressing health disparities in the United States.

CAPITALS AND CAPABILITIES

Pierre Bourdieu's work regarding social structure and Amartya Sen's capabilities approach help to contextualize disparities in health care, especially when considering the needs of racially diverse veterans. Specifically, Bourdieu's concepts of *capital* and *habitus* taken together with Sen's capabilities approach can provide a framework for understanding root causes of health disparities and for health care providers and policymakers to use in taking action to reduce said disparities.

Capital Interaction and Habitus

Pierre Bourdieu introduced the idea that capital should be considered as three distinct forms: economic, social, and cultural (Bourdieu, 1986). *Economic capital* is what we traditionally think of when we think capital: money and material assets. Economic capital is a decisive factor when considering relative social position between groups and is fundamental to the development of both social and cultural capital. *Social capital* refers to resources, both material and non-material, that can be mobilized via relationships with friends, family, or colleagues. Thus, social capital can be understood as an individual's social network or the extent to which an individual can leverage relationships with others for their own benefit. Lastly, *cultural capital* is broadly defined as an individual's resources for action. Cultural capital can include an individual's skills and knowledge, objective tools such as books, and institutional power such as a college degree (Bourdieu).

Lifetimes are spent struggling to acquire and apply the differing forms of capital. The likelihood of being successful is influenced by a person's habitus. Habitus is the field of play that governs people's actions and attitudes in the everyday world. That is, an individual's experiences, socialization, and circumstances predisposes the individual towards a specific behavior, and behavioral choices are typically in keeping with the norms of an individual's group or social class (Blaxter, 2004). Consequently, habitus greatly influences capacity to acquire capital. Capital, in turn, influences the ability to act in favor of health (Abel & Frohlich, 2012).

An important point about Bourdieu's concept of capital is that despite their separateness, the three forms of capital are interrelated and inextricably linked. The acquisition of social capital frequently depends on the possession of cultural capital: certain values, behaviors, and knowledge are put into motion by people in order to

participate in desirable social networks (Abel & Frohlich, 2012). Likewise, cultural capital frequently depends on economic capital. For example, one must invest money to further one's education. From this theoretical perspective, it is these linkages between types of capital that demonstrate how health disparities occur: *capital interaction* contributes to the reproduction of social inequalities in society (Bourdieu, 1986), and these lead to disparate health outcomes.

Capabilities Approach

While Bourdieu's work is useful in contextualizing the role of habitus and capital in the reproduction of social inequalities, it is not intended as a guide as to how to change these structural factors. This is where Amartya Sen's (1992) capabilities approach is helpful. Proposed as an alternative to traditional welfare economics, the capabilities approach holds *individual well-being* as the outcome of a just society and defines well-being as an individual's ability to pursue activities he or she has reason to value. The capabilities approach explicitly rejects a focus on the *means* to achieve freedom (e.g., money or other material goods) as the appropriate outcome of a just society as this singular outcome would fail to account for the diversity of the human experience (Sen, 1992). This framework has received considerable attention in the fields of human development, education, and economic policies, and it is beginning to be recognized as a useful framework for understanding and addressing social inequalities and health disparities.

The term *functionings* is used to denote *well-being achievement* in the capabilities approach. Functionings represent the things that a person succeeds in being or doing. Examples of beings (i.e., what you are) are healthy, happy, physically fit, or well-nourished. In contrast, examples of doings (i.e., what you do) are exercising, reading, or eating. According to the capabilities approach, a person's well-being is an index of his or

her functionings, and the functionings emerge from their *capability set* (Sen, 1985). The capability set, in turn, is defined as an individual's opportunities for achieving things he or she has reason to value. Thus, the capabilities set represents the *well-being freedom* of a person in that it encompasses the range and variety of choices available to a person. Importantly, the capabilities approach values both the capability and not just the functioning as the outcome of interest as the capability allows us to consider the real opportunities available to a person. Sen (1992) contends that the ability to choose between meaningful options is itself a valuable part of living, and a life with meaningful choice can be considered to be of higher quality. Doing "x" can be quite different than choosing to do "x" and then doing it.

In addition to the critical distinctions between the aforementioned concepts, an additional aspect of the capabilities approach that must be understood is its attention to the diversity inherent in human lives. The characteristics of goods do not tell us what the person will be able to do with those goods. Indeed, the resource requirements to convert a commodity into a valuable functioning vary considerably depending on contingent circumstances (Sen, 1985). Individual variation such as innate talent, genetic predispositions or physical differences combined with the individual's social context (e.g., social norms, laws, institutions, family, peers, neighborhood) and systematic differences between groups results in some groups having much less freedom to pursue meaningful activities than others (Sen, 1992). The capabilities approach uses the concept of conversion factors to account for this diversity in circumstance. Critically, capability does not refer exclusively to a person's abilities but also includes real opportunities made possible or constrained by conversion factors. When considering an individual's opportunities to "achieve functionings that he or she has reason to value" (Sen, 1992, p. 5), it is of paramount importance to consider conversion factors as individuals have

varying needs for resources in order to achieve the same level of capability (Sen, 1992). Therefore, relying on equality of distribution of resources (such as access to health care) will not result in equality of freedom to pursue well-being.

Sen (1985) has used a bicycle analogy to demonstrate the centrality of conversion factors. A bicycle is commonly looked upon as a convenient mode of transportation. However, the mere presence of a bicycle does not produce the functioning of transportation. If a person is physically unable or has never learned to ride a bicycle, the bicycle is not useful. If a woman is able to ride a bicycle but social norms do not allow women to ride bikes, the bicycle is not useful. Likewise, if there are no safe routes for bicycling, the bicycle remains an interesting commodity, but it has not been transformed into the valuable functioning of transportation. Thus, it is not enough to know about the things a person owns or uses to sufficiently assess well-being. The social circumstances and environment in which the person lives are also determinants of well-being. In the next section, capitals, habitus, and capabilities will be used in an analysis of racial disparities in a specific subset of veterans receiving care in the VHA.

VETERANS HEALTH ADMINISTRATION

The VHA is the largest provider of integrated health care services in the U.S. with over 1,700 sites of care, serving almost nine million veterans each year (VHA, 2015). It is characterized as open access, meaning that all authorized veterans may use VHA ambulatory care services without paying annual premiums (Washington, Villa, Brown, Damron-Rodriguez, & Harada, 2005). Not all veterans may access health care through the VHA; eligibility is prioritized based on service-related disabilities and income level. Low-income veterans without a qualified disability can receive care via the VHA to the

extent that funding allows, and veterans earning incomes slightly higher than the thresholds can access the VHA with co-payments (Bernard & Selden, 2016).

Roughly two-thirds of veterans accessing health care via the VHA are over the age of 65, have higher rates of comorbid physical and mental illness, and have lower incomes than age-matched non-veterans (VHA, 2014). The remaining one-third of veterans using the VHA are mainly those who have been deployed since September 11, 2001, and for whom physical and emotional trauma related to repeated and prolonged deployments are common health issues (VHA). Females currently represent approximately 8% of the U.S. military, but female veterans are more likely to report enrolling in the VHA system for health care than are males (33% and 26.1% respectively) (Westat, 2010). Due to the criteria limiting open-access to those with financial need and those with a service-related health condition, veterans who access health care via the VHA, on average, have low income, are unlikely to have other forms of health insurance, report poorer than average quality of life, and suffer from multiple physical and mental comorbidities (Lypson, Ross, Zimmerman, Goldrath, & Ravidranathan, 2016).

Embedded within the mission of the VHA to "honor America's Veterans by providing exceptional health care that improves their health and well-being" is a duty to achieve equity in health care for all veterans (VHA, 2015). Health equity has been defined as the "absence of systematic disparities in health between social groups who have different levels of underlying social advantage" (Braveman & Gruskin, 2003, p. 256). America's veterans deserve exceptional health care regardless of social class or race, and the VHA continues to strive towards this mission. However, health equity is not yet a reality within the VHA.

RACIAL DISPARITIES IN THE VETERANS HEALTH ADMINISTRATION

There are well-documented racial disparities between African American and non-Hispanic white veterans across a broad range of health indicators (Saha, et al., 2008). Two indicators studied within the VHA are the utilization and outcomes of total joint replacement/arthroplasty (TJA) for the treatment of osteoarthritis (OA). The racial disparities in TJA among veterans accessing care from the VHA serves as an illustrative case study as to the role of capital and capabilities related to health. An explanation of OA and the burden of OA among military veterans is provided for context.

Osteoarthritis. Osteoarthritis (OA) is the leading cause of physical disability and functional impairment among older adults in the U.S. (Igrit & Nelson, 2011). OA is characterized by pain, aching, stiffness, and loss of function in the affected joint. Consequently, OA has considerable impact on quality of life, health care costs, and well-being as people with OA report lower levels of health-related quality of life, and medical charges for patients with OA are nearly twice that for people without OA (Dominick, Golightly, & Jackson, 2006). There are over 52 million adults with self-reported doctor-diagnosed OA, and 22.7 million adults report limiting activity due to OA (Centers for Disease Control and Prevention [CDC], 2013). Females have a higher risk of developing OA as do people who are overweight or who have a previous joint injury (Desphande, et al., 2011).

Most likely due to the strenuous nature of the military training and combat environment, military veterans have a higher prevalence of physician-diagnosed OA than non-veterans, and veterans using the VHA for health care have a higher prevalence than those accessing health care via the private sector (Dominick, Golightly, & Jackson, 2006). Overall, veterans have a high burden of OA as 34.7% report physician-diagnosed OA compared with 24% of non-Veterans (Murphy et al., 2014). Further, veterans develop

OA at a younger age than the general population, putting them at increased risk for adverse outcomes related to OA as well as creating extra burden for the health care system as a whole (Murphy et al.).

There is an effective surgical treatment for OA, and OA is the leading indicator for total joint arthroplasty (TJA) (Irgit & Nelson, 2011). TJA replaces the diseased joint with an artificial joint and has been proven to reduce pain and improve function and quality of life when non-surgical methods are unsuccessful (National Institutes of Health [NIH], 2003). Total knee arthroplasty (TKA) and total hip arthroplasty (THA) are the most common joint replacement procedures.

Disparities in Total Joint Arthroplasty

Utilization. Several studies confirm significant racial disparities in TJA utilization among Medicare beneficiaries (Kane, Wilt, Suarez-Almazor, & Fu, 2007). While illuminating an important disparity, these studies are limited by the fact that Medicare beneficiaries are typically over 65 years of age, and there is a significant population of people with OA under the age of 65. Therefore, the VHA database has been used to provide a more nuanced exploration into racial disparities in TJA utilization. An analysis of the records of 260,856 veterans confirmed that racial disparities persist in this younger and less advantaged demographic (Jones, Kwoh, Kelley, & Ibrahim, 2005). In that analysis, after controlling for age, sex, and number of comorbidities, African American patients with a diagnosis of lower extremity OA were significantly less likely than white patients to undergo TKA within the two-year follow-up period (OR 0.72, 95% CI 0.65-0.80) (Jones, et al.).

Outcomes. In addition to the significant differences in TJA utilization, there are also significant differences in post-surgical complications between African American and white veterans. Ibrahim, et al. (2005) analyzed records of 12,108 patients who underwent

TKA during a five-year period to identify rates of non-infection-related complications such as thrombosis as well as infection-related complications such as urinary tract infections, surgical site infections, and sepsis. While overall complication rates were low, they found that, compared with white patients, and after controlling for demographic factors, comorbidities, and hospital surgical volume, African American patients had a significantly higher relative risk of both non-infection-related complications (RR 1.50, 95% CI 1.08-2.10) and infection-related complications (RR 1.42, 95% CI 1.06-1.90) after TKA (Ibrahim, et al.).

Given the data, it is evident that differences in TJA utilization and outcomes exist between African Americans and white patients in the VHA. Due to the significant negative impacts of OA and potential positive impacts of TJA, it is important to identify the reasons for these differences. As an open access system, the VHA serves as its own control for the potential confounders of insurance status or unequal access to care (Washington, et al., 2005). Thus, the racial disparities evidenced in the VHA should not be attributed to these factors.

African Americans and non-Hispanic whites suffer from symptomatic OA at similar rates – 7.5% and 6.9%, respectively (Desphande, et al., 2016), and African Americans and whites have similar prevalence rates of OA-related functional limitations (American Academy of Orthopaedic Surgeons, 2010; Golightly & Dominick, 2005). Studies have also shown that, after controlling for other demographic and clinical factors, African Americans report a higher level of symptom severity than whites (Golightly & Dominick). Thus, it can be assumed that the racial disparity in TJA is not due to differences in disease prevalence or severity.

If neither differential access to health care nor differences in prevalence or severity can explain the racial disparities, what, then, can? The literature presented below

is organized around patient-, provider-, and system-level factors as potential explanations for the observed racial disparities.

Reasons for Disparities from the Literature

Patient-level factors. Ibrahim, Siminoff, Burant, and Kwoh (2002a) found that patient willingness influenced the utilization of TJA. Specifically, African American patients were significantly less likely than white patients receiving care at VHA outpatient clinics to consider TJA as a treatment option (OR 0.50, 95% CI 0.30-0.84). The reluctance can be at least partially attributed to less familiarity with the procedure as African Americans were less likely to have heard of TJA, to know someone who had undergone the procedure, or to have a good understanding of what TJA entailed. African Americans also reported lower expectations for positive surgical outcomes and greater expectations of prolonged recovery (Ibrahim, et al.). These findings are in keeping with previous studies that found African American patients to be less willing to undergo elective cardiovascular procedures (e.g., Sedlis, et al., 1997).

A review of studies from the VHA indicate that African American veterans are more likely than their white counterparts to rely on self-care practices such as over-the-counter pain medication, reducing activity, and seeking advice and assistance from friends or family for managing OA (Rowley, Jenkins, & Frazier, 2007). African Americans were also found to be more likely to subscribe to traditional therapies (e.g., physical therapy) and complementary treatments (e.g., copper bracelets, herbal medications) for managing OA. In contrast, white veterans were more likely to view nonsurgical options as ineffective (Rowley, et al.).

Provider-level factors. There is evidence that differential treatment by or communication with providers contributes to racial health disparities. Hausmann and colleagues (2010) found that after controlling for age and severity of OA, orthopedic

surgeons were less likely to recommend TJA to African American patients than to white patients (OR 0.46, 95% CI, 0.26-0.83). Further analysis found that the racial disparity was non-significant after adjusting for patient preference. This supports the aforementioned lack of willingness by African Americans to undergo TJA.

System-level factors. While the VHA-based literature does not specifically investigate the issue, the non-VHA literature acknowledges the potential system-level factor of African Americans being more likely to receive care at low-volume hospitals (Epstein, Gray, & Schlesinger, 2010). That minority patients are more likely to undergo surgery at low-volume hospitals is a disparity that warrants investigation in and of itself, as low-volume hospitals have been correlated with increased risks of surgical complications (Dy et al., 2014; Singh, Kwoh, Boudreau, Lee, & Ibrahim, 2011).

Taken together it is evident that patient-, provider-, and system-level factors contribute to racial disparities in TJA utilization and outcomes among veterans using the VHA for health care. The literature stops short, however, in examining underlying reasons for these factors. A closer examination can yield a greater understanding of their socially-situated origins.

CAPITALS AND CAPABILITIES TO EXPLAIN RACIAL DISPARITIES

Connecting Bourdieu's concepts of capital interaction and habitus with Sen's conversion factors makes evident that any analysis of disparities in health must consider different life circumstances and thus differing capabilities to convert material resources into valuable functionings. Based on the analysis of racial disparities in TJA utilization among veterans accessing care in the VHA, it is clear that despite equal access to health care, differing social circumstances for African American veterans may result in the lack of capital that is required to convert this resource into a realized functioning.

As previously mentioned, veterans accessing the VHA for health care have a lower than average income, are unlikely to have other forms of health insurance, report lower than average quality of life, and suffer from multiple comorbidities (Lypson, Ross, Zimmerman, Goldrath, & Ravidranathan, 2016). Among veterans with OA who were included in analyses of TJA utilization and outcomes, compared with their white counterparts, African Americans consistently had significantly lower incomes, less education, and lower self-reported quality of life as well as being less likely to be employed (Jones, et al., 2005; Ibrahim, et al., 2002a; Ibrahim, et al., 2002b; Ibrahim, Stone, et al., 2005). Thus, even in a population that is decidedly worse off than the general public, African Americans fare worse.

The VHA-based studies did not specifically analyze education levels, but a non-VHA-based study found education levels to be a significant predictor of TJA utilization. Using data from the U.S. Health and Retirement Survey, Steel and colleagues (2008) analyzed records of 14,807 people over the age of 60 and found not only that African Americans were significantly less likely to undergo TJA than whites (OR 0.34, 95% CI. 0.17-0.66) but also that those without a college education were less likely to have undergone TJA (OR 0.65, 95% CI 0.44-0.96). Assuming these results would generalize, African American veterans are doubly disadvantaged in this scenario: they are less likely to receive needed treatment because of both their minority status and because they are less likely to have a college education. This compounded disadvantage reinforces the concept of capital interaction.

It was noted that African Americans were significantly less likely to be familiar with TJA and were, therefore, less likely to be willing to undergo TJA as a treatment for OA (Ibrahim, Siminoff, Burant, & Kwoh, 2002a). The increased risk of post-surgical complications among African American veterans is likely another contributing factor to

this reluctance. That African Americans were significantly more likely to belong to social networks in which TJA is not commonly utilized and in which post-surgical complications are higher is evidence of unequal levels of social capital as it regards health care utilization. The lower level of social capital can reinforce the habitus of not electing surgical intervention even when indicated.

The unequal distribution of capital among veterans using the VHA for health care essentially negates the promise of the VHA as an open access system. According to the capabilities approach, when interested in well-being, the capability of African American veterans to convert resources into functionings should be analyzed. That is, it is not sufficient to evenly distribute access to health care without considering the ability of different groups to make effective use of that resource (i.e., conversion factors). Because of disparate circumstances, African American veterans may not effectively access or use health care; thus, the habitus of routinely denying appropriate surgical intervention for a chronic, disabling condition is established. It should be noted that likely there are many individuals in this population group who would still refuse TJA as a treatment option even with an adequate capability set. But, the capabilities approach demands that each individual has equality of freedom, not equality of outcomes, meaning that we must work to ensure the capability sets of African American veterans are equal to those of their white counterparts. The remainder of this article will present an argument that using the capabilities approach as the theoretical framework for health-related public policy can move us beyond a discussion related to the distribution of health care and provide a means to evaluate the real opportunities available to people.

A Capabilities Approach to Justice in Health Care

In a much-lauded effort to address the persistent issue of timely access to care for all entitled veterans, in 2016 the VHA amended its regulations to allow advance practice registered nurses (APRNs) full practice authority when they are working within their scope of employment with the VHA (Federal Register, 2016). This rule has the potential to distribute the VHA health care resources more effectively while maintaining a focus on patient-centered care. We commend the VHA for recognizing the important role that APRNs play in the American health care system and contend that insofar as additional health care resources are available, APRNs are uniquely educated and thus ideally situated to ensure that the social and environmental context (i.e., conversion factors) are routinely assessed and accounted for when delivering health care. However, data indicate that better availability of high quality health care will address only 10-15% of preventable mortality in the U.S. (e.g., McGinnis, Williams-Russo, & Knickman, 2002; Woolf & Purnell, 2016). Empirical evidence of racial disparities in the VHA supports our claim that health disparities can be attributed to inequitable capital and capability sets stemming from social and structural factors outside of the health care system. Therefore, distribution of additional health care resources will not be sufficient to alleviate health inequities.

That the distribution of health care resources is insufficient to address social and environmental concerns is not new. Indeed, a 1974 Canadian report concluded that health care does not have the power to fully mitigate the threats posed by unhealthful environments and behaviors (Lalonde, 1974). Since then, researchers have routinely documented the interconnectedness of health, well-being, and social context, and yet there has been very little progress in the way of alleviating disparities in health that are rooted in social inequalities. To us, this is an indication that policymaking has not yet

caught up with the research and has therefore been unable to address the larger social inequalities that manifest as health disparities. We argue that this is at least partially attributable to the lack of a conceptual framework that can accommodate a concurrent focus on the quality of health care and the social context in which health occurs. The capabilities approach allows for this concurrent focus.

We endorse the broad application of the capabilities approach for use in addressing health disparities because of the explicit focus that it gives to the issues of health equity, health inequality, and social arrangements. Because of the immense reach of health equity, Sen is unequivocal in his stance that "health equity cannot be understood in terms of the distribution of *health care*" (Sen, 2002, p. 660). He goes on to say that health equity must take into account how social arrangements and resource allocations are linked with health. He is clear that the health of less advantaged groups can be improved by altering social arrangements or resource allocations, and we must not merely assume that efforts towards health equity necessarily come at the cost of other groups' health care resources or health achievement. Thus, the capabilities approach does not emphasize the equalization of access to resources for all citizens. Instead, we must thoughtfully consider Sen's question *equality of what*? Due to the diversity inherent in the human experience, equality in one space can result in marked inequality in another (e.g., equality in access to health care can result in quite unequal levels of health). Thus, Sen (1992) contends that the evaluative focus must be on the capability set—that is the well-being freedom of a person. A focus on the capability set broadens the evaluative space to include the conversion factors (i.e., individual characteristics as well as the social and environmental context) that may facilitate or impede an individual's ability to convert the resource of health care into the functioning of health.

In addition to defining the evaluative space as a person's capability set, the capabilities approach helps to define the value of health for society. In the context of policy design, the ultimate objectives will depend upon what we value for society and what we are trying to maximize. Thus, we must be clear on our value judgment regarding health. The capabilities approach values health for both its *intrinsic* value and its *instrumental* value in expanding a person's capability set. Situating health care within this context of health as a *means* to an end in addition to an end itself can facilitate an understanding that not only does social context directly affect health, but the lack of opportunities to pursue valuable activities could prevent a person from pursuing health or health care in the first place. For example, we can begin to understand that not only does social context affect health directly (e.g., lack of access to health care, high levels of air pollution, unaffordability of nutritious foods), but the lack of meaningful opportunities in a person's life (e.g., a well-paying job, affordable child care, and enjoyable social connections) could prevent a person from pursuing health or health care in the first place. This could be due to the capability set not being large enough to accommodate the pursuit of multiple ends thereby health is set aside to pursue a more basic need. Alternatively, if health is the means to a more meaningful life, without meaningful opportunities available, there may be less reason to pursue health.

In early 2016, Kottke, Stiefel, and Pronk called for a shifting of the broad aim of policy from health to well-being. They argued that this shift would appropriately place health among the determinants of well-being, as opposed to the ultimate aim, and that policymakers and service providers could more easily recognize nonclinical opportunities to improve well-being while not abandoning their mission of providing health care. Additionally, a broad aim of well-being as the goal of policy instead of an exclusive focus on health outcomes or cost of care has the potential to invite policymakers from

sectors such as education or housing to rightfully join the challenge to address health disparities. The socially situated origins of disparate capital and inadequate capability sets that result in health disparities necessitates a cross-sectoral approach to addressing them. It is naïve to think that the health care system alone can or should bear the entirety of responsibility for alleviating health disparities.

We agree with the call to shift the broad aim of policy to well-being with the caveat that it be done in accordance with the framework outlined by the capabilities approach. While there is general agreement that well-being encompasses more than just physical health, there is no universally agreed upon definition of well-being. Thus, without a framework, we risk the expansive definition of well-being as the real opportunities that a person has to pursue activities he or she values for more traditional notions of well-being as synonymous with welfare. As previously discussed, defining well-being in terms of a person's income (or other material goods) does very little in the way of moving us towards a consideration of how "well" one's "being" truly is (Sen, 1985). Additionally, the capabilities approach as the guiding framework retains the capability set as the evaluative focus. Examining the real opportunities available to a person in concert with factors from his or her social context that may hinder or facilitate the conversion of resources into valued functionings provides space for multi-sectoral efforts.

Despite the need for a broad-based effort aimed at alleviating health disparities, the health care system must also shift to include factors beyond the traditional scope of clinical indicators and service delivery, and it is beginning to do so. With enactment of the Patient Protection and Affordable Care Act (ACA) in 2010, the federal government included some provisions aimed at transforming the health care delivery system in an effort to reduce health disparities. Specifically, accountable care organizations (ACO) are

based on the tenet that health care providers should work together at the system level to proactively manage population health and be reimbursed for value-based care, moving away from the traditional fee-for-service arrangements (U.S. Department of Health and Human Services, 2015). However, value is a subjective term, and without careful attention to the policy mechanisms at work, we risk exchanging care that the patient values (and will, therefore, seek) for 'high-value care' that is defined along the lines of "the health outcomes achieved per dollar spent" (Porter, 2010, p. 2477). If value-based care is neither reflective of care that patients value nor of their social context, it is unlikely to have any meaningful effect on the pervasive and persistent disparities in health in our society and may, in fact, perpetuate the disparities. Thus, the importance of the capabilities approach for use in the planning and evaluation of policy and service delivery related to value-based care is revealed: without it, we will certainly be at risk of neglecting the patient perspective.

In 2016, the U.S. Department of Health and Human Services announced funding for an innovative model that is intended to bridge the gap between the health care and social services sectors. The accountable health communities model focuses on connecting clinical services with community resources to address the broad range of social needs that can harm health (Centers for Medicare and Medicaid Services [CMS], 2016). Entities eligible for funding include community-based organizations, health care provider practices, hospitals and health systems, universities, local government entities, and tribal organizations (CMS). The funded entity becomes the lead organization in establishing an accountable health community through partnership with the state Medicaid agency and via the establishment of a referral network that links health care providers with community service providers. We are cautiously optimistic about the promise of this

model. We suggest the capabilities approach for use in the development and implementation of accountable health communities across the U.S.

CONCLUSION

The example of racial disparities in TJA utilization among veterans demonstrates that access to health care is not sufficient for achieving equity in health care. The theoretical explanation that is carefully detailed in this article suggests that deep-seated social inequalities are at the root of the health disparities that are manifested within the context of the American health care system. While this article uses a specific subset of veterans to underscore the importance of considering social circumstances, the theoretical explanation of health disparities need not be limited to this population. The well-documented gaps in health between social groups can be explained by inequitable distribution of capital stemming from, for example, structural barriers such as discrimination in housing policies (Madrigal, 2014). Thus, while the VHA may have an increased sense of urgency due to the current publicity around quality and access, an expanded framework based on the capabilities approach is needed across all health care sectors.

Even in this time of widespread system transformation, the elimination of health disparities will remain an optimistic yet elusive ideal if social inequalities are not addressed. We have proposed the capabilities approach as a framework that is well-suited to consider individual patient values, the social context in which health occurs, and the need for multi-sectoral collaborative efforts. We contend that a capabilities approach within the U.S. health and social services sector can move us past the false premise that changing social inequalities and investing tax dollars in social and community programs always represent zero-sum activities where those with more resources need to share with

those with few resources (McGinnis, Williams-Russo, & Knickman, 2002). Instead, a capabilities approach can move us towards a discussion of how to make effective use of the resources that are available.

Chapter 4. A grounded theory study of well-being among rural-dwelling adults with disabilities

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ABSTRACT

Disability is a significant issue among rural-dwelling, working age adults. The purpose of this study was to develop a substantive theory to explain how working-age adults with disabilities living in rural counties in Texas define and pursue well-being. Twelve rural-dwelling participants were interviewed from one to three times in order to understand the processes involved in defining and pursuing well-being. From this constructivist grounded theory exploration, it is suggested that well-being is situated and relational. That is, well-being is not a set state to be achieved and then enjoyed; rather well-being results from establishing and maintaining membership in the rural community. Membership, in turn, facilitated access to the broad array of material and psychological supports needed for a sense of well-being. The findings from this study support the long-held assumption that models developed in urban areas are insufficient for the health and well-being of rural residents. The proposed substantive theory provides an understanding of how rural-dwelling adults with disabilities mobilize individual and collective resources in order to overcome functional limitations and environmental barriers to establish group membership and create a sense of well-being. Implications for healthcare practice and policy development are discussed.

Disability among working-age adults is a significant issue in rural America, and evidence suggests a systematic relationship between impairment rates and geography (von Reichert, Greiman, Myers, & Rural Institute, University of Montana, 2014). In 2016, there were approximately 46 million Americans who lived in rural areas of the United States, accounting for about 14% of the American population (United States Department of Agriculture [USDA], 2017). While rural Americans account for a relatively small percentage of the total U.S. population, they represent a higher proportion of people who have a disability: 17.1% of rural Americans report some type of disabling condition compared with 11.7% of adults living in urban areas (RTC: Rural, 2017). The higher rates of disability persist across gender, race, impairment type, and all age groups. Additionally, analysis of 2008-2016 Current Population Survey data (CPS; See Table 1 for disability definitions) led to identification of a rural disability penalty. That is, rural-dwellers report rates of functional limitations that are similar to their urban counterparts who are 10 years older (RTC: Rural, 2017).

Despite the documented disparities in disability between urban and rural areas, we know very little about the experience of living with a disability in rural America. This is problematic given the well-documented influence that social and environmental factors have on health outcomes and well-being for people with disabilities (e.g., Carmona, Giannini, Bergmark, & Cabe, 2010; Drum, 2014; Harrison, Umberson, Lin, & Cheng, 2010). Indeed, the same impairment in a different social context can have drastically different consequences for individual lives (Vehmas & Shakespeare, 2014). The goal of the present study was to build a substantive theory to explain how adults with disabilities living in rural counties in Texas define and pursue well-being. This will be accomplished in three steps. First, I will review previous theoretical and empirical work regarding rural health disparities and disability in the United States. Next, I will present the current study

and the findings. Last, I will discuss implications of the findings for rural healthcare service delivery, research, policy, and program development.

BACKGROUND AND SIGNIFICANCE

The 2010 National Healthcare Disparities Report highlighted the significant disparities related to healthcare access between rural and urban areas (U.S. Department of Health and Human Services [USDHHS], 2011), and the National Institutes of Health (NIH) recognizes people living in rural areas as a health disparity population due to the higher prevalence of disease and premature mortality rates for rural-dwellers (USDHHS, 2009). Indeed, research has identified substantial and increasing urban-rural disparities in life expectancy over time. In 1969-1971, the gap was 0.4 years; in 2005-2009, it had widened to 2.0 years (Singh & Siapush, 2014). Nationwide, the highest all-cause mortality rates for working-age adults are found in the most rural counties (Meit et al. 2014). This pattern holds true for ischemic heart disease, chronic obstructive pulmonary disease, unintentional injury, and suicide (Meit et al. 2014). Evidence also suggests that health-promoting behaviors are lower among rural-dwelling populations. For example, adults living in nonmetropolitan counties are more likely to be current smokers and are less likely to maintain normal body weight and to meet physical activity recommendations (Matthews et al., 2017).

Evidence demonstrates that rural areas across the U.S. have a disproportionate share of individuals from sociodemographic groups at high risk of poor health outcomes: those with low income, low educational attainment, and of advanced age (Meit, et al., 2014). While these risk factors are not unique to rural populations, the rural environment may pose distinct environmental and structural barriers that may heighten the relative risk of these socioeconomic influences and may pose even greater obstacles for adults with

disabilities. For example, rural residents in general face significant challenges in accessing both primary and specialty healthcare (Iezzoni, Killeen, & O'Day, 2006). Due to their increased likelihood of being uninsured, lacking access to transportation, and needing medical attention on a more frequent basis (Davidsson & Södergård, 2016; Krahn, Klein Walker, & Correa-de-Araujo, 2015), rural residents with disabilities may be doubly disadvantaged by the limited healthcare services available in rural communities. Indeed, it has been documented that adults with disabilities living in rural areas typically rely on services that are more informal and less specialized; must travel farther and pay more for those services; and, when they do access services, tend to receive lower quality care than their urban counterparts (Whitener, Weber, & Duncan, 2001). Previous research also identified that barriers to health practices are greater in rural persons with multiple sclerosis and that the relative importance of individual barriers varied based on rural or urban location (Stuifbergen, 1999).

The above-mentioned problems with rural health are commonly-cited and important concerns that underscore the necessity of understanding the experience of place, space, and time involved in health and well-being for people with disabilities who live in rural areas. Rural well-being is theorized to consist of the subtleties of social relations interlaced with the history and culture of the environment in addition to access to health care services (Brown & Swanson, 2003). Rural Americans have been described as independent and self-sufficient, distrusting of outsiders, and having a strong sense of place (Coyne, Demian-Popescu, & Friend, 2006; Long & Weinert, 1989; Phillips & McLeroy, 2004). The value that rural-dwellers place on the shared meaning of their culture may have a direct and distinct impact upon an individual's well-being because of cultural expectations regarding social role performance or social activities. Indeed, Harrison (2009) stated that age-based cultural norms have a direct bearing on the process

of disablement. She argued that the fulfillment of a social role is dependent upon individual ability but also upon cultural expectations of roles and behaviors. Eng, Salmon, and Mullen (1992) argued that important determinants of health-related behavior are rooted in the intricate relationships between individuals, organizations, neighborhoods, families, and friends. Thus, it is important to understand how rural-dwelling individuals with an impairment that may hinder the fulfillment of normative social roles and cultural expectations adapts to their impairment and mobilizes resources to overcome barriers and pursue well-being.

Given the limited access to healthcare resources, the complexity and cost of healthcare, and the sociodemographic risk factors of rural residents, how the rural culture influences health and well-being should be considered a priority for policymakers. Interventions and policy solutions for rural-dwelling adults with disabilities may need to reflect the rural culture, social expectations, and shared values. The current qualitative study was designed to be an initial step towards filling the gap between documented disparities and understanding the significance of the sociocultural environment in establishing and reproducing health and well-being. Ultimately, a better understanding of how complex social processes operate for rural-dwelling adults with disabilities can move us towards culturally-appropriate services embedded within local areas that capitalize on existing strengths and resources.

SENSITIZING FRAMEWORK

A sensitizing framework that incorporated symbolic interactionism (SI; Blumer, 1969) with tenets from Amartya Sen's capabilities approach (1992) was used to structure the data collection and analysis in this grounded theory study of well-being among adults with disabilities living in rural communities. The foundation of SI is comprised of three

assumptions: 1) people strive and act toward what represents meaning for them, 2) meaning arises out of social interaction, and 3) meaning is dealt with and modified through interpretive processes (Blumer, 1969). Thus, a core tenet of SI is the inseparability of the individual and the context within which that person exists.

SI is rooted in the American pragmatist tradition and holds that our sense of self is constructed in relation to how we view ourselves and how other people view us. Mead (1934) argued that outward influences on human behavior are mediated through meanings resulting from previous experiences and social interaction. Thus, the images of others and their actions toward us shape how we see ourselves and, in turn, shape our actions and beliefs. SI recognizes that the individual is separate from the world, but asserts that the world is interpreted by the individual through symbols and during interaction. Using SI as a sensitizing framework facilitates an examination of the preconditions necessary for human agency and the meanings associated with various actions (or inactions).

The capabilities approach (Sen, 1992) holds that when evaluating well-being, the capability to function—that is, what a person can do or be—is preferred to the traditional focus on variables such as income, wealth, or happiness because it more adequately captures the diversity inherent in the human experience as well as provides space for human agency. The capabilities approach explicitly acknowledges that variation in innate talent, genetic predispositions, or physical differences combined with systematic differences between groups results in some individuals and groups having much less freedom to pursue meaningful activities than others. Thus, depending upon one's circumstances, he or she may require different kinds or different amounts of goods or commodities in order to be able to transform those resources into valued outcomes. When

using the capabilities approach, the ability of a person to transform resources into well-being must be considered.

These tenets from the capabilities approach provided a point of departure for this study. Using a capabilities perspective to investigate the lives of rural adults with disabilities facilitated an understanding of the processes by which individuals in this population are empowered to make decisions about important aspects of their life, how they convert their resources into valued activities and outcomes (e.g., working, participating in social activities, being healthy), and how they assign meaning to and place value on particular outcomes.

METHODOLOGY

After approval from the university institutional review board, a constructivist grounded theory study (CGT; Charmaz, 2006) using the constant comparative method of data analysis (Strauss & Corbin, 1998) was initiated. Grounded theory was designed to reveal the human process of change in response to life circumstances and is especially useful when existing research has left major gaps (Schreiber & Stern, 2001). It is also a powerful tool for social and health science because it facilitates a deep and nuanced understanding of what is going on within a particular setting and in response to specific conditions (Morse et al., 2009).

Because the subjective experiences of adults with disabilities residing in rural areas of the United States are not well-represented in the healthcare literature to date and because of the usefulness of grounded theory in studying how people manage their lives in the context of actual or potential challenges, CGT was chosen as the methodology for this study. CGT recognizes that meaning is constructed through ongoing interaction with others as well as through historical and cultural norms that operate in people's lives

(Charmaz, 2006). This approach allowed the researcher to address the processes of interaction among individuals as well as the structures that influence that interaction.

PARTICIPANT RECRUITMENT

To be included in this study, participants had to be between the ages of 35-70 years of age and respond "yes" to one of the following subset of questions from the American Community Survey (U.S. Census Bureau, 2014) designed to identify people who may experience mobility, hearing, and/or vision impairments: 1) do you have serious difficulty walking or climbing stairs, 2) are you deaf or do you have serious difficulty hearing, and/or 3) are you blind or do you have serious difficulty seeing, even when wearing glasses? Further, participants were required to reside in a county in Texas classified as non-core (typically defined as <10,000 residents) according to the Office of Management and Budget (OMB) rural classification codes (USDA, 2017), be community-dwelling, understand spoken or written English, and be able to communicate verbally in English or through an interpreter.

A strategy employing multiple recruitment methods was used to facilitate recruitment (Patton, 2015). First, the 74 counties in Texas classified as 'noncore' were identified and located on a map (See Figure 1). Because of the expansive geography of the state of Texas and to maximize study resources, six of the 74 counties were chosen to target recruitment efforts due to geographic proximity to the university at which the researcher is located. After the six target counties were identified, efforts were made to locate community gatekeepers, stakeholders, and resources in each of them, and diverse media formats were used to reach potential participants.

Community gatekeepers. Because evidence indicates the need to build trust with rural community members and to be endorsed by social or church groups (e.g., Burns,

Soward, Skelly, Leeman, & Carlson, 2008; Loftin, Barnett, Bunn, & Sullivan, 2005), the first step in the recruitment strategy was to identify and make contact with community gatekeepers. Community gatekeepers were identified based on initial research regarding resources and people in each of the targeted communities. First, the name and contact information of the Veterans Services Officer in each targeted county were located. Next, a list of faith communities in each targeted county was compiled. Methodist Healthcare Ministries based in San Antonio, Texas, employs Wesley Nurses (serving in a capacity similar to parish nurses) in Methodist congregations across south and west Texas; therefore, Wesley Nurses serving in Methodist churches in three of the six targeted counties were identified and contacted. Finally, outpatient healthcare facilities in the counties were identified. After identification of these community gatekeepers, initial contact was made with each via phone call, e-mail, and/or face-to-face visit.

Media strategies. Because researchers have reported mixed results from advertising via traditional media outlets such as newspaper classified advertisements (Loftin, Barnett, Bunn, & Sullivan, 2005; Stuifbergen, 1999), the researcher chose to place a classified ad in two of the targeted counties. The first ad ran weekly for four consecutive weeks during the first month of recruitment. The second ad also ran weekly in an adjacent county for four consecutive weeks during the third month of recruitment. In addition to the traditional newspaper media, research study information was provided by a community gatekeeper via web-based formats. Specifically, one of the pastors of a local church in one of the targeted communities was enthusiastic about supporting recruitment efforts for this study. Therefore, his church advertised the study on their Facebook page, via their weekly e-mail newsletter, and in their Sunday church bulletin.

Informal networks. Because the researcher was an outsider seeking access to multiple rural communities, she relied heavily on the informal networks that are so

important in rural areas (Coyne, Demian-Popescu, & Friend, 2006). During initial visits to the targeted counties, the researcher visited local barber shops, pharmacies, retail stores, health department offices, community action agencies, and other community entities to introduce herself and the study and to ask for suggestions as to how to access her target population. During these visits, she would leave several recruitment flyers with the person to distribute to others they may know. The researcher also used her own informal connections to gain access to the population.

SAMPLING METHODS

Initially, purposeful sampling was used to identify participants for the study. Consistent with purposeful sampling, the researcher targeted those who met the initial criteria of age, rural residence, and disability. As the study analysis matured, theoretical sampling became necessary. That is, the initial open-ended interviews identified concepts that became the basis for subsequent sampling. Therefore, theoretical sampling helped to ensure that the researcher gained the perspective of people with experiences in the theoretical area. The researcher also used theoretical interviewing in order to elicit information and perspectives about the theoretical concepts. For example, faith was identified as an important concept early on during data collection. Therefore, in order to gain a nuanced understanding of faith in rural Texas, the researcher enrolled a participant who met the inclusion criteria and had been a pastor in several small communities across the state. The researcher also asked subsequent participants about their faith beliefs and what role, if any, faith plays in their life with a disability. Later, specific efforts were made to identify racial and ethnic minority participants to include their perspectives in the emerging theory.

Theoretical sampling facilitated the ability to compare participant experiences, check and refine the boundaries of identified categories, and discover variation within the categories (Charmaz, 2006). After the core category was identified and during the selective coding stage of data analysis, the researcher recruited one urban-dwelling participant with a physical disability. This was necessary because understanding the boundaries of this study and the theoretical concepts could only be determined through the use of negative stories from individuals not representative of the emerging theory.

ETHICAL CONSIDERATIONS

Participant Enrollment. Twenty-two people contacted the researcher via phone, via e-mail, and/or gave a gatekeeper a message consenting for contact. Each potential participant was called by the investigator, screened for inclusion, and informed of the study details. This initial discussion included a preliminary review of informed consent procedures. After these preliminary steps, a total of 12 people remained qualified and interested in the study. With this pre-screened and informed group of people, a time and place to meet was determined. All interviews took place in the rural community in which the participant lived. Depending upon the preferences and abilities of the participants, research interviews were conducted in participants' homes, offices, public libraries, or local cafes. In three instances, follow-up interviews took place in a different location than the first. For example, if the first interview was conducted in a local café, the follow-up interview was conducted at the participant's home.

Prior to the date of the first interview, the researcher mailed the informed consent document and three survey instruments via United States Postal Service to the participants at their home address. Included with the research instruments was a cover letter explaining the study and the documents.

Informed Consent. Participants were told they would have the opportunity to ask any questions prior to initiation of the interview. At the beginning of each interview, the researcher asked the participant if he or she had any questions. After any questions were answered, informed consent was obtained.

Incentives. Financial incentives have been identified as a successful motivator for participation in research studies (Friedman, Foster, Bergeron, Tanner, & Kim, 2015). Furthermore, paying research participants serves as a token of appreciation for their contribution to a study thereby reinforcing the trust that is essential to the researcher-participant relationship, but the amount of money offered should not be so large that it is likely to be coercive nor should it be so small that it leads to exploitation (Resnik, 2015). Therefore, after consultation with an expert in qualitative research, participants were offered $25.00 for each interview.

Confidentiality. Participants were assigned a participant ID by the researcher; this ID was used to identify participants on all written documents and on audio files and interview transcripts. Individual names were linked to the ID in a password-protected spreadsheet available only to the researcher. After transcription of the interviews and verification of the transcriptions by the researcher, audio recordings of the interview were destroyed. All efforts have been made to keep the identities of the research participants anonymous; therefore, pseudonyms are used throughout this paper. Participants were asked if they had a preferred pseudonym; if they did, that name is used. Otherwise, pseudonyms were assigned by the researcher. Further, because of the small communities from which these participants were recruited, some identifying diagnoses were changed. This was to ensure that any future readers of the study would not be able to identify a participant based upon a distinct diagnosis or condition.

Referral. As part of the informed consent process, participants were told that if they shared with the researcher that they were being abused or neglected they would be referred for assistance. Additionally, participants were told that if they scored above 13 on the Kessler-6 Psychological Distress Scale (K6; Kessler et al., 2003), they would be assessed for suicidal ideation and provided contact information to local mental health providers.

DATA COLLECTION

The goal of data collection was to discover the meaning of well-being to rural-dwelling adults with disabilities and to build a substantive theory of the pursuit of well-being based on an understanding of the life experiences of working age adults with disabilities. Data were collected from 12 rural-dwelling and one urban-dwelling, community-residing individuals with various disabilities. Data included 20 interviews lasting 1.5 to 3 hours each, field notes, and memos of theoretical reflections and insights. Data collection and analysis took place over seven months between June 2017 and February 2018.

Interviews. The guiding question for this study was "how do rural-dwelling adults with disabilities define and pursue well-being?" In order to answer this query, open-ended questions relating to when and how the initial impairment occurred, perceptions of how the impairment has affected the participant's life over time, and activities that he or she enjoys doing were asked. Participants were also asked to discuss positive and negative qualities of their rural communities, to describe people with whom they interact on a regular basis, to explain their typical daily routines, as well as if and how their disability affected relationships and routines. As the study continued and data analysis began to suggest categories, interview questions were refined based on the

identified categories in the evolving theory in order to refine concepts. Thus, later interviews were theoretical interviews with a focused approach in order to elicit dimensionality and nuance of the theoretical concepts. For example, an early category identified from the data was "belonging." After this category was identified, during subsequent interviews, the researcher asked participants to describe the place where they would feel most at home or would be the best fit for them physically, socially, and materially.

Field notes. Field notes were written after each participant interview and during initial visits to the targeted counties in order to document firsthand the activities in which participants engaged and the contexts in which those activities took place. Field notes included observations about the town or community in general: were there people out and about? Was there a town square? Was it well-kept? Were there sidewalks? In what condition were the roads? Were there any restaurants or obvious gathering places for community members? How was the researcher received by community members she talked with? Field notes also included observations about the participants and their immediate environments: did they use an assistive device? How did they navigate their environment? Were they well-kept and neatly groomed? Did they seem physically fit, frail, overweight, or something else? In what condition was their home? Was there evidence of family or friends? Thus, the data in the field notes helped to identify, explore, and explain the social structures and contexts of the participants.

Demographic Questions. Demographic data was collected via a demographic questionnaire. This questionnaire can be found in Appendix B. Data collected include: age, race/ethnicity, length of residence in county, educational level, income level, housing type, family structure, employment status, occupation, and age at onset of impairment.

Standardized Surveys. Information on well-being was also collected via two standardized well-being instruments, both found in Appendix B. The Kessler-6 Psychological Distress Scale (K6; Kessler et al., 2003) is a six-item screening scale to identify nonspecific psychological distress in the general population (Kessler et al., 2002). The questions ask respondents how frequently they experienced symptoms of psychological distress (e.g., feeling so sad nothing can cheer you up) during the past 30 days. Responses range from "none of the time" coded 0 to "all of the time" coded 4. The six items on the scale are then summed to yield a number 0-24 with a score $\geq$ 13 indicating non-specific psychological distress and possible serious mental illness (Kessler et al., 2003). The scale has demonstrated excellent internal consistency and reliability (Cronbach's alpha=0.89) (Kessler et al., 2002). The ICECAP-A (Al-Janabi, Flynn, & Coast, 2011) is a measure of capability for the general adult population and focuses on attributes of well-being (Al-Janabi et al., 2013). The five well-being attributes are attachment, stability, achievement, enjoyment, and autonomy. Each attribute can take one of four levels ranging from full capability to no capability (Flynn et al., 2015).

DATA ANALYSIS

Data analysis of interview transcripts and field notes focused on the meanings, intentions, and actions of the study participants using the constant comparative method of analysis (Strauss & Corbin, 1998). The constant comparative method of analysis calls for coding to be initiated immediately after the first interview and repeated for the duration of the analysis. Based on experiences of researchers in previously published grounded theory studies, as participants contacted the researcher, interviews were scheduled even if coding of prior interview transcripts was not complete (Harrison, Umberson, Lin, &

Cheng, 2010). This helped to prevent potential participants from declining to be interviewed if they were asked to wait until an unknown future date to participate.

Each interview transcript was read multiple times in order to gain a sense of the whole before beginning open coding. Open coding is used to identify initial meaning and involves identifying, naming, and categorizing data via line-by-line analysis (Glaser, 1978). During this stage, theoretical memoing was begun in order to begin to frame the conceptual ideas about the identified codes. Axial coding is the next step of data analysis (Strauss & Corbin, 1998). During this step, initial codes were collapsed into broader axial codes in order to analyze linkages between concepts that can connect categories and subcategories at a conceptual level.

The last step undertaken was selective coding. Selective coding is the process of choosing one category to be the main or core category and then relating all other categories to that one (Strauss & Corbin, 1998). After the core category was identified and selective coding begun, the remainder of the data collection and coding was restricted to that which is relevant to the emerging theory. During this process, our analytic team came together on six occasions to examine the emerging theory for logic, conceptual clarity, defining borders, and explicating relationships between concepts. Case-based dialogues were used among the group to convey the process of pursuing well-being as a rural community member with a disability. Specifically, the primary investigator (who collected the research data) presented cases to the team that she believed represented emerging categories. Through dialogue, the team refined and combined early categories such as “negotiating expectations” and “strategizing to normalize life” into the analytic category “demands” and combined “balancing opportunities” and “maximizing opportunities” into “strategic participation. “Engaging in reciprocal relationships” and “belonging” were abstracted into the core category “membership.”

Another strategy used to aid in the process of selective coding was the development of matrices as the categories were constructed. The matrices cross-listed emerging categories with answers to the questions: what, when, where, why, how, and with what consequences actions occurred. The matrices facilitated identification of the core category and its descriptors. Finally, Figure 2, found in Appendix A, was developed and continuously refined throughout the data analysis process in order to fully conceptualize and relate the categories.

Data collected in the field notes were incorporated into the final analysis of the theory. This was done by engaging in theoretical memoing throughout the data collection and analysis phase of the study. The theoretical memos enabled the researcher to transform the descriptions of social context found in the field notes into theoretical accounts explaining the conditions and pre-conditions that predicted behaviors. As an example, the field notes of one interview contained data about the participant's perceptions of the lack of formal services for people in his age group living with a disability in rural Texas. This data was extracted into a theoretical memo regarding the importance of informal networks and how, in lieu of formal services, these informal networks were leveraged to have needs met. This early memo provided structure for the development and refinement of the emerging theory. Additionally, details of participant responses to questions and demeanor during the research interviews were included in the descriptive account of the theory presented in this paper.

The quantitative data collected via demographic surveys and standardized well-being instruments were qualitized in order to extract additional information and to confirm interpretations (Sandelowski, 2000). This was accomplished by incorporating the scores and rankings from the well-being instruments into field notes. This helped to compare qualitative interview data and researcher observations and insights recorded in

field notes against objective standards for measuring well-being. That is, the researcher was able to compare participants' subjective interpretations of well-being against what is measured in the standardized instruments. For example, one participant in particular struggled with her declining physical and social capacity; this was evident in her interview as she was unable to effectively participate in the social processes needed to pursue well-being. Comparing her interview data with the well-being instruments indicated that her inability to engage in the important social processes identified in this study did influence her well-being as she indicated moderate psychological distress and ranked herself fairly low on the well-being attributes included on the ICECAP-A. Thus, this comparison enabled the researcher to further check the boundaries of the emerging theory by analyzing participant stories against their well-being scores. This process also served as a method of triangulation thereby enhancing the transferability of the study.

Transferability is defined as the way in which qualitative studies can be made applicable to broader contexts while still maintaining context-specific richness (Ravitch & Carl, 2016). In this study, transferability was also addressed by providing detailed descriptions of the participants, the data, and the context and by reporting of data using participants' direct quotes. To enhance credibility of the data analysis and interpretations, an audit trail was maintained throughout the data collection and analysis process, and the author reviewed emergent interpretations with an expert in qualitative methodologies and disability.

Reflexivity is important in qualitative research as the researcher's personal background, culture, and experiences can potentially shape the interpretation of data (Creswell, 2014). Therefore, reflexivity was maintained through on-going documentation in a research log, juxtaposing these reflections against the data, and discussing the reflections with an expert advisor. As an example, the researcher studied interview

transcripts with an expert in qualitative methodologies in order to interrogate implicit assumptions made by the wording of questions or probing for context and specifics. The researcher also listened to the audiotaped interviews to examine the extent to which she allowed for generative pauses. Insights gained from these types of reflective exercises were recorded in the research log and studied in order to stay true to the intent of the research: an exploration of the complexity of participants' experiences of living with a disability in rural Texas from their perspectives.

SAMPLE

A sample of 12 rural-dwelling and one urban-dwelling adults ages 35-70 years participated in this study (See Table 2). The mean age of the rural participants was 60.5 years (SD=8.16). In general, the study participants were primarily married, older, white women who used accommodations for mobility or hearing.

To be more specific, eight (67%) rural participants were women. Ten (83%) of the rural participants identified as non-Hispanic white, one (7%) identified as African-American, and one (7%) identified as 25% Native American and 75% non-Hispanic white. The timing of impairment among the participants ranged from four to 59 years of age. All participants reported a functional limitation because of mobility and/or sensory impairments; three also reported a mental health diagnosis. Reasons for impairments included osteoarthritis, multiple sclerosis, neurodegenerative illness, acute hearing loss, genetic hearing loss, diabetes, and heart disease. Ten of the 12 rural participants (83%) used some type of assistive device or accommodation; the participant from the urban county also used an assistive device. Two (15%) used wheelchairs, and one of these also had a service dog; three (23%) used walkers or canes depending upon where they were;

two (15%) had personal attendants; two (15%) used hearing aids; one (7%) used a power lift chair at home and occasionally used an electric scooter when running errands.

Of the rural participants in this study, eight (67%) were currently married, one (8%) had never been married, one (8%) was divorced, and two (15%) had been widowed. Nine (69%) had children, and four (30%) had grandchildren. All of the participants had graduated from high school, eight (61%) had earned either an Associate's Degree or a Bachelor's Degree, and three (25%) of the rural participants had completed a graduate degree. In spite of the high level of education of this sample, only one (8%) of the rural-dwelling participants worked full-time. Three of the participants worked only part-time because of their disability, two were self-employed and worked to the extent that opportunities were available and their individual capacity allowed. Two of the participants had taken early retirement. Three (23%) were unemployed, but only one of those participants was actively seeking employment. At the time of the study, four (30%) rural participants reported having difficulty making ends meet and relied upon some type of public assistance such as SNAP benefits or a community food pantry; two others reported having used public assistance in the past.

Participants lived in six different counties in Texas. The mean population of the rural counties was 6,828 (See Table 3). None of the participants had spent their entire lives in their current community, but 10 (76%) participants had lived in their current locations for more than 15 years. Four (30%) of the participants had been born and raised in urban areas.

Two participants scored over the cut-point of 13 on the K6 scale indicating serious psychological distress. Both of these participants were asked if they were contemplating suicide or were having suicidal thoughts. Both denied any current suicidal ideation, but one of them did report having had suicidal thoughts in the past. Both

participants were referred to local mental health providers. One of these participants reported a diagnosis of bipolar disorder and being under the care of a psychiatrist; she was provided with additional information on local social service agencies for assistance with income and job placement.

On the ICECAP-A, participants generally indicated the ability to have "a lot" of love, friendship, and support; to feel settled and secure in "all" or "many" areas of their lives; to be "completely" independent or independent in "most" things; to achieve and progress in "some" or "few" areas of life; and to have "a lot" or "quite a lot" of enjoyment and pleasure. Participants who scored highest on the K6 (indicating psychological distress) scored lowest on the ICECAP capability well-being scale.

FINDINGS

In this study, I sought to understand well-being from the perspective of rural-dwelling adults with disabilities along with the social processes involved in creating and pursuing well-being amongst this population. Thus, I explicated how and why people construct their beliefs and values to arrive at a self-identified sense of well-being; how they manage their lives; and why they think, feel, and act the way they do for that purpose. What is clear from this study is that for these participants, well-being is situated, dynamic, and relational. That is, rather than a set state to be achieved and then enjoyed, well-being is emergent and facilitated over time through the interaction between personal, cultural, and environmental structures and processes.

This section holds the main finding of the study, which is that well-being is intricately linked with living in community with others in accordance with shared history and personal values and to the fullest extent of one's abilities. This assertion will be reinforced by developing the following six conceptual categories that lead to a core rural

membership that drives well-being: values, a rural attitude, demands, set expectations, strategic participation, and membership. These concepts will be defined, and theoretical dimensions will be explored and reinforced by providing participant quotes and examples. In the next sections, I provide a clear understanding of the experience of rural individuals who live with physical and/or hearing impairments.

Values

Participants identified several values—those beliefs that guide their actions and appraisals of their actions and environment. These included faith, belonging, doing for others, hard work, family, freedom, independence, accountability, security, and proximity to nature. The identified values permeated the actions taken and decisions made to participate (or not), and the sense of congruency between participants' individual values and the cultural values and norms of the rural environment contributed to the development and maintenance of a rural attitude, which is discussed in the following section.

Rural communities were described as places where people hold one another accountable and lift one another up, where people respect one another and treat one another as family, and where one can still get things done with a "handshake agreement." That is, mutual trust and respect between community members allowed opportunities for resolving difficulties without the need for outside intervention or extensive formal oversight. In turn, this facilitated a sense of freedom to pursue creative collaboration to overcome some of the difficulties associated with living in a rural area. For example, Charlie described working with a nearby jurisdiction to secure transportation for disabled veterans from his rural county to the nearest VA facility. He said,

> "…see, this is how easy these problems are to fix if you – I mean, we just got on the phone. It took about two months because it involved federal money, and there had to be a little paperwork, now…but in the end, it was a handshake agreement, and it works great. And as dumb as I am, I was able to solve an issue with some help from some other folks and a little PR and just, you know, just sticking with it."

This description of hard work and perseverance was echoed by many of the participants.

Another shared value was a strong Christian faith reflected in a commitment to others and to the community. Cathy, reflecting a common sentiment, said simply, "my faith is everything. I do not understand people who don't have faith." Faith played two key roles in participants' lives: a source of comfort and guidance and a source of community and belonging. Many described turning to God for solace in times of hardship and believing that strength to overcome pain, functional limitations, and poor health came from God. This is not to say that participants had a fatalistic perspective on life but rather recognized a personal responsibility for cultivating well-being. Bryan clearly described this perspective when he declared that refusal to seek help, engage in therapy, or take prescribed medications is "denying God the ability to help work through this." Similarly, Sharon recounted that her faith has guided her to take better care of herself, and after her mother passed away in 2011, she stopped drinking alcohol and has lost over 100 pounds. Participants also explained their reliance on "God's rules." For example, Joe began every day by praying and reading his Bible. He explained his faith saying "he [God] has rules that we need to go by, and that's helping others whenever we can, and we only live by that."

In addition to providing a source of resolve, determination, and a set of rules for living, faith in God also facilitated a sense of community and belonging. In these rural areas, the church was valued for its role as a cultural institution that provided resources, services, and support for community members in need. Charlie, who did not identify as

particularly religious, nevertheless valued the church and recognized its importance, saying,

> "if you are an active member in church, and we have 20 here I believe, you have a church family that will come check on you and keep track of you, but if you're not, then you need to have good neighbors or some kinfolk somewhere because there's nobody to go around and see these folks."

Debbie valued the community available to her through her church. She preferred small churches because "you get to know the people better" and was able to form friendships more easily. She also appreciated the ability to be more helpful to others in smaller congregations because it was always known who was in need. Katherine shared this preference for small churches and described attending services by herself in order to identify a congregation in which she felt welcomed. For Katherine, who struggled with mental illness in addition to physical limitations, attending church services on her own underscored the value she placed upon a comfortable, welcoming, and small church family.

Participants also valued home and family, and to many, the land on which they lived provided a symbolic connection to home and family over time. Linda described the 84-acre ranch that her great-grandfather settled in the 1870s. She and her family continue to live and raise horses on the remote expanse of rocky terrain on the border of the hill country in Central Texas. Their mobile home had been destroyed by a tornado in 2016, so their family of four was living in a camper trailer while they built a small cabin on the property as a permanent dwelling. Despite the inconvenience of a temporary residence ill-suited for a long-term stay and the increasing difficulty that she has navigating the rugged terrain and engaging in the manual labor that ranch life entails, the enduring ties to the land connected Linda across generations and provided her with a sense "as though your ancestors are still there to support you." Similarly, when asked what her community

meant to her, Katherine said simply "family." She and her husband had recently relocated from outside of Dallas back to her hometown in order to help care for her aging parents. Katherine gained personal benefit from living in her small community again, but the impetus for the relocation was a commitment to family.

A Rural Attitude

Having a rural attitude was an essential component of membership. In the current model, a rural attitude is defined as a choice to center the popular representation of the rural idyll while also recognizing the social, economic, and political realities of their remote or sparsely populated communities. For this study, rural was operationalized using an absolute, geographic definition—counties in Texas categorized as non-core—but for these participants, having a rural attitude encompassed a relational understanding of rural. That is, rural was not a static state delimited by geographic boundaries but rather was symbolic and constituted of experiences and interpretations. This relational understanding of rural is in line with definitions of rural put forth by health geographers who have sought to identify spatial and place-based approaches to rural well-being (Halfacre, 1993; Woods, 2011). A relational approach to rurality has been described as an emphasis on the significance of networks and connections and holds that all entities, human and non-human, are "equal components within a network, each with a capacity to change outcomes through their participation or non-participation" (Woods, p.41). Similarly, in this study, a rural attitude was not defined as an idle state of being and living in a sparsely populated or remote area. Rather, having a rural attitude was characterized by participating in shared practices, supporting one another, possessing a deep knowledge of and appreciation for the materiality of the place and was developed in contrast with and relative to urban space and society.

For participants who had been raised in rural areas, a rural attitude was engrained in their belief systems. People took pride in understanding the people and the rural way of life and took action to protect and honor the shared values. For example, after spending his career as a computer programmer—first for the military and later for IBM—living and working in cities across the United States, Robert took early retirement in order to re-connect with his west-Texas roots. He moved to a 17-acre ranch located in a remote part of a rural county in Central Texas where he lives alone in a two-room log cabin and where he raises cattle. To Robert, his continued ability to live and work the land—despite difficulty navigating the terrain, losing money on the endeavor, and missing opportunities to find a romantic interest—connected him to a proud tradition of "country folk" whereby he could embody the "cowboy code" of being dependable, hard-working, and independent.

Developing a rural attitude happened over time for others. For example, Sharon was born and raised in a mid-size city in southeast Texas. Before she could incorporate the rural community values into her own belief system, she had to first understand the rural people and way of life. She recounted a violent childhood and explained that "where I'm from people being called friendly is not a good thing." She contrasted this with the friendliness of the people in her adopted hometown of about 1200 people near the Texas/Mexico border. Sharon has lived in her current community for almost 20 years, and over the course of that time, she has adjusted to people recognizing her, calling her by name, and generally looking out for one another. Over time, she adopted a rural attitude, saying "I'm a country girl now." At the time of the study, Sharon believed herself to be capable of both giving and receiving support and assistance when needed despite her functional limitations, poor mental health, and fixed income.

All participants interpreted their rural lives in contrast to their time spent in urban environments. This is not surprising as rural has always been defined and imagined as relative to urban space and society (Woods, 2011). In contrast to the familiarity of the rural area, participants perceived that in a city, people are invisible and nobody really cares. Participants valued being known to others, and this was facilitated in their small communities via everyday exchanges (e.g., being greeted by name at the health clinic or when walking down the street), organized events (e.g., church activities, community festivals), or employment activities (e.g., interviewing community members, assisting veterans to gain services). Additionally, participants described a sense of unease when reflecting on the urban area. Bryan described his discomfort, saying:

> "… there are issues that begin to be um, well, there are issues that are just – they're – that I'm not as comfortable dealing with, or as –as in – I don't understand gangs. I don't understand, uh, the drug trade as it happens in those kinds of places…um, as an individual, it benefits me in that it provides me a space where I – my family – where I can raise my family and feel – have a sense of security that I do not have in, um, the more urban situation."

The rural participants uniformly regarded urban environments as loud, stressful, chaotic, and expensive and valued the calm, quiet surroundings of the rural areas. Misty described living in the country. She said,

> "the land comes to own you, you don't own the land, you know. This is – it's the wealth that is indescribable. Uh, you go to the city and it's cacophony, it's –it's people everywhere, it makes me nervous. I can't stand it."

Regardless of barriers inherent to rural areas such as limited access to healthcare services, participants credited the slower pace of life in the rural environment with many health benefits. Not worrying about traffic, crowds, or loud sirens, for example, enabled participants to relax and more easily engage with family and friends. Katherine, who struggles with PTSD and bipolar disorder in addition to mobility limitations stemming

from osteoarthritis, was able to attend a bi-weekly support group because she did not have to worry about encountering noisy crowds while she was out and about. Bryan credited the fact that he had not had an exacerbation of his multiple sclerosis in many years to living in the less stressful rural environment. Debbie (who has early-onset hearing loss) clearly revealed the value of the physical proximity to nature by describing how she once on a cold, still evening heard a coyote howling in the distance. She remembered that experience as "awesome" and valued the opportunity to live in an area where such an experience was possible.

Having a rural attitude entailed valuing communities, homes, land, animals, and/or faith communities and feeling positive about the rural environment even while acknowledging that small communities are not perfect. Participants reconciled with the difficulties in accessing goods and services, the impertinent questions asked by nosy neighbors, and the relative lack of entertainment options by focusing on the positive aspects of their communities. For example, participants appraised the value of accessible and familiar healthcare services available to them in the rural area as outweighing the difficulty associated with extended travel for specialty care. This is not to say that participants did not express concerns about their healthcare. Indeed, some shared specific examples of clinical policies contradicting their lived experiences. For example, Charlie, the first army veteran with whom I spoke, expressed dismay at the VA's policy of requiring a certain BMI before performing a knee replacement. He said,

> "You know, this has nothing to do with my will to keep going. I know folks in this town who had knee replacements and they have a good Body Mass Index. And the only thing they do is go from the recliner to the bathroom and back to the recliner. That's all they do. And, uh, I know; I've watched them. And so, I thought, 'this is a little frustrating with government medicine because they make it one-size-fits all'."

Similarly, Linda recounted being instructed not to lift anything over 5 pounds after a back surgery some time ago. Her incredulity at this instruction was evident as she rolled her eyes while saying, "on a ranch?!"

Despite the incongruity of clinical advice with individual lives and values, the ability to see providers who knew them, who recognized them when they were there, and who seemed to be generally interested in them as people made up for these shortcomings for many participants. Indeed, the informal social relationships between participants and their healthcare providers were important. Misty, who traveled an hour and a half for specialty visits described the convenience of attending the same church as her primary care physician. Describing one evening at a Bible study, she said,

> "my doctor was there. I could stop, and it's like, 'excuse me, I've got this cat bite,' and he wrote out a script, called it in to the thing. I mean, listen, that doesn't happen in a big town."

Participants also assessed what was frequently described as the annoyance of "everyone knowing their business" by interpreting the meaning of this aspect of small-town living: when they are in need, people know it and will take action to ensure that needs are met. This was in stark contrast to Jennifer, the urban-dwelling participant. Jennifer described actively seeking groups of other wheelchair users in order to avoid impertinent questions asked by non-disabled friends and strangers. She valued community but did not interpret these types of questions as well-intentioned. Thus, she actively sought solace with others who shared similar physical limitations.

Demands

In the current model, demands represent the product of participants' ongoing judgments about the influence of disability or impairment on their ability to participate in their communities. Thus, demands are defined as disability-related events that can be

appraised as difficulties or as challenging opportunities for growth. This definition is in keeping with the demands of illness construct whereby demands of illness are illness-related events experienced by individuals or families in response to health problems and are not identical to illness stressors, hardships, or problems (Woods, Haberman, & Packard, 1993). Examples of demands shared by these participants include educating others about their impairments, strategizing to normalize life, and managing expectations.

Most participants perceived a social demand to educate others about their impairments. Often, this took the form of proactively warning others of what they perceived as personal shortcomings. One participant with chronic pain and physical impairments told a potential employer, "I'm unreliable" in order to prepare the employer for a potentially unpredictable work schedule. Another participant regularly told peers and colleagues, "I can't hear well" and asked them to look directly at her when speaking. Participants also asserted their abilities to others in order to continuously challenge social perceptions of people with disabilities. One participant told family and friends, "I'm not dead yet" despite having a need to do things a little differently than they do.

Many participants approached demands as opportunities for growth. For example, Debbie understood the need to educate others about her hearing impairment, but living in a rural area, she now feels welcomed and accepted because of her hearing impairment, not in spite of it. Therefore, she approached the social demand to educate others as an opportunity to help older adults who were experiencing hearing loss for the first time. She said, "when you go through something, you want to share it." Similarly, when Linda and her family were severely cash-poor due to bills stemming from her medical care, they relied on the community food bank for assistance. She recognized the hardship associated with being in such financial straits, but she appraised the situation as an opportunity to appreciate that help was there for her when she needed it, and she now volunteers at the

food bank on a monthly basis. In contrast, Jennifer, the urban-dwelling participant did not embrace the social demand to educate others about her disability as an opportunity for growth. She understood and accepted this demand, but she preferred her time spent in environments that were adapted for wheelchair users and surrounded by others who shared the experience of disability.

Participants strategized to normalize life to facilitate social participation in the community. For example, in his community where many men work in the oilfields, Bryan re-organized his day to begin at the local coffee shop at 4:30am so that he could engage with them. Over time, he expected to meet certain people, and he became a familiar face to the other men in his community. This expectation of encountering and interacting with others reinforced the importance of participation and served to establish membership in his community. Similarly, because Joe expected to encounter known others during his daily routines, he ensured that he was always dressed appropriately and neatly groomed before leaving the house. This consistent presentation of himself to community members served to reinforce a perception of himself as a capable and trustworthy group member who should not be reduced to his disability.

Having an impairment was perceived as a fact of life experienced as an everyday condition. To the extent that this was true, participants' disabilities did not greatly impinge on their sense of self or the mutuality of their interactions. That is not to say that disability was dismissed as participants certainly recognized that their ability to navigate situations was limited or at the very least different than that of others. For those who experienced greater severity of illness or impairment (Stuifbergen, Seraphine, & Roberts, 2000), managing demands was more difficult. One participant in particular experienced disability demands that ultimately resulted in a reappraisal of self and identity. Cindy regretted the tears she shed as she discussed the difficulties involved with her day-to-day

life saying, “I don’t want to be so emotional. I’m a tough cookie.” However, she experienced many demands that took an emotional and physical toll on her as she continuously reappraised her ability to participate as a member in her community. For Cindy, living in a small, rural area created additional demands. No one else with her diagnosis lived in her community, so she perceived a demand to educate others about her diagnosis. However, the uncertainty of her everyday life, the progression of her illness, and her shrinking social network had prevented this education from taking place. Further, there were no support groups or opportunities to engage with others who had experienced or were currently experiencing similar degenerative conditions. This limited her ability to anticipate her future in the long-term and to make plans on a daily basis. She said, “this disease has taken me away from my city, my business – It hasn’t taken me away from my family yet, but it’s trying.”

Set Expectations

Participants in this study set expectations regarding their everyday lives in their rural communities, and these expectations contributed to a rural attitude and to strategic participation. Expectations or expectancies can be defined as the act or state of looking forward to or anticipating an event or an outcome (Williams, Anderson, & Winett, 2005). Expectancies are a major component of many cognitive motivation theories (Atkinson, 1964; Bandura, 1986; Maier & Seligman, 1976), and favorable outcome expectancies influence subsequent behavior by reinforcing or renewing effort. In contrast, if expectancies are sufficiently unfavorable, the result is reduced effort or even complete disengagement (Scheier & Carver, 1985). The rural community allowed participants to adopt and master daily routines that facilitated participation in the community. The meanings attributed to specific actions developed over time via these routines. These

participants—who had mobility and/or hearing impairments—developed expectations within the parameters of their abilities and their communities, and the smaller, more predictable rural environment facilitated set expectations.

Despite set expectations of what the day could or should hold, for some participants, routines fluctuated due to the unpredictable nature of their impairments. Thus, routines were dependent on whether the day was a "good" day or a "bad" day. On good days, participants were able to engage in everyday activities such as getting dressed, going to work, feeding the livestock, or going to church without much trouble. On bad days, however, routines were greatly altered. For example, instead of going to his part-time job at the local courthouse or tending to his donkeys and goats, Charlie would be unable to get out of bed and would therefore stay in bed until his pain was controlled and he was again able to function. He said,

> "Um, on bad days, you know, when you can't do what you need to do, it makes one feel useless or inadequate, but I'm not a depressing kind of person, so I don't – I just wait until the next day, hoping that it will be better."

As they adapted to changes in physical capacity or to economic constraints, many participants altered their regular routines to accommodate declining abilities, but the rural environment served as a buffer of sorts against potential negative psychological effects of declining physical or social capacities. This was due to people being more constant in the small rural communities. That is, there was not as much coming and going of outsiders, and people were familiar to one another. As they engaged in daily routines over time, participants expected to interact with certain known others, and mutual trust and respect had developed. Therefore, as participants were less able to do the things they did before, even mundane encounters could be meaningful. Being greeted by name when walking down the street or entering the community bank provided a sense that participants

continued to be recognized as trustworthy community members. In turn, this sense of being known to others served as a feedback loop and provided incentive for participants to continue to engage in their routines and to participate in order to maintain membership in the community even on days when it was difficult to do so.

Strategic Participation

In the current model, strategic participation is defined as selective and planned involvement with and within the physical, social, cultural, and economic context and was not characterized by the type or amount of activities in which participants engaged. Rather, participants emphasized the ability to freely choose to participate or not in order to satisfy needs for competence, autonomy and reciprocity. Further, because of their functional limitations, participants did not impulsively decide to participate; they strategically chose what courses of action to pursue and then developed detailed plans for successful participation. Thus, strategic participation can be viewed as an ongoing process as well as a means by which specific social roles and expectations are fulfilled. In order to successfully negotiate this ongoing process, participants engaged in an ongoing appraisal of abilities, desires, and opportunities and managed demands in order to participate in their communities in ways that they found meaningful and satisfying and that helped to establish or maintain their group membership.

As participants engaged in relationships and assumed various roles, they continuously appraised their own perceptions of their abilities, what they perceived others' perceptions of their abilities to be, and the opportunities that were available to them. Based on this ongoing appraisal, participants often worried about how or if they could meet all of their social commitments. However, in accordance with the "cowboy code," participants did not give themselves a break. Instead, they worked to ensure that

all of their obligations were met even if it resulted in worsening health status. One participant attributed a recent bout with pneumonia to his "hard-headedness" and refusal to stop working. Over time, however, participants realized that some relationships and activities were not worth the physical or emotional toll, and they re-organized daily tasks and routines in order to re-prioritize valued activities and set aside those which were less meaningful or which produced unneeded stress and anxiety. For example, opportunities that were perceived to be difficult or challenging in some way were frequently passed by as navigating daily life was challenging enough. However, letting go of activities or relationships required balancing as fewer opportunities for engagement could result in feeling of loneliness or isolation. Indeed, participants identified that the relative isolation of the rural communities created barriers to establishing long-term, close relationships. Thus, participants carefully balanced their desire for close personal connection and opportunities for engaging with others with their physical and/or emotional capabilities.

If participants' appraisals of the meaning and importance of the activity outweighed the barriers, they would choose to participate. Frequently, they would choose to participate even though participation would result in personal discomfort or inconvenience. For example, after reading that many people with her condition socially isolate themselves because of the severity of their symptoms, Cathy specifically took action to prevent this from happening. She said,

> "I made myself get out and go, and my husband, we'd go to the movies and stuff with friends. I'd tell him, I'd say 'Okay, I can't hear y'all. So, y'all just let me sit over here in the car and go with y'all. Y'all don't leave me out. You take me with you."

Similarly, Joe, who lamented being unable to work a regular full-time job due to his impairments and chronic pain, continued to work his part-time job to the best of his ability. He emphatically stated "I will not let my disability tie me down." Misty valued

her membership in a local social group and proudly served in several leadership roles. However, the clubhouse where the group met did not, until a recent renovation, have an accessible restroom for her. In order to participate in the group meetings and functions, Misty ensured that she had a female urinal in her van to use if she needed to urinate.

Participants also carefully appraised available opportunities. Frequently, participants had to balance activities that honored family and community with opportunities for career advancement or more money. When discussing his clergy appointment to his current location, Bryan said "this was a step down, career wise." But, he prioritized the needs of his family over his personal desire for career advancement. A common refrain was "I'm not doing this for the money" when asked about current employment, and three of the rural-dwelling participants refused the $25.00 participant incentive for this study. Instead, participants wanted opportunities to be useful, to contribute to their communities, and to be allowed to choose how and when to act.

Importantly, participants were discerning in their pursuit and acceptance of employment opportunities. Only one of the rural-dwelling participants worked full-time. Bryan had been born and raised in rural Texas, and over the course of his career, he interpreted his ability to be successful in his career as a result of his understanding rural culture and values. Thus, Bryan had carefully pursued opportunities that enabled him to remain in rural areas in Texas thereby balancing his desire to have a successful career with one that enabled his membership in a community with shared history and values. Other participants worked part-time in order to balance physical capabilities with the expectations of employers as well as the scope of work required. That is, participants who worked part-time strategically sought positions that were flexible and in line with their personal values and abilities. Thus, employment created opportunities for social participation and contributions to their communities, thereby facilitating membership. In

contrast, participants who were unemployed lamented the lack of opportunities for meaningful interaction and contribution more than the lack of income or benefits. They did not feel shame or stigmatized at their need to rely on public benefits or community members' generosity as it was acknowledged that "everybody needs help sometimes." Instead, non-participation in the economic sector was interpreted as preventing full and equal membership.

Membership – The Core Category

The main concern for this sample of working-age adults with disabilities was *membership* in their rural community. Early researchers in the area of group membership (Aronson & Mills, 1959; Buss & Portnoy, 1967) posited that membership is a belief that one has invested part of his or herself to become a member and therefore has a right to belong. In the current theory of well-being among rural adults with disabilities, membership is defined as a feeling of belonging and being part of something greater than one's self sustained by ongoing contributions to the collective. This sense of establishing and maintaining membership and subsequently belonging to a group dominated how participants described their personal histories and lived experiences and accounted for the majority of the variation in the data. Well-being hinged on being part of a collective that was able to mobilize to meet social, psychological, and material needs.

Regardless of whether participants were raised in rural or urban areas, membership in the rural community was important, and participants deliberately pursued courses of action that would establish or maintain their social standing and, thus, membership in the rural community. The meaning of membership varied, however, depending upon childhood experiences, participants' interpretations of those experiences, and the reactions of others to their current life situations.

Participants who had suffered abuse during their childhoods grew up cultivating survival skills and choosing actions to both separate them from their abusers and to foster membership in the communities they now call home. These participants described childhoods spent yearning for escape from their abusers and a desire to take a different path in their own lives. For example, Joe described being severely beaten by his stepfather during his childhood in a large urban area in the northeast and said that his family was "not a well family." Joe was ashamed by what he perceived as a lifetime of idleness and desolation on the part of his extended family. Thus, he joined the army, earned an associate's degree, and relocated to rural Texas where, despite chronic pain and limited mobility, he works part-time in a role that allows him to help other veterans and he also volunteers for various community service activities. These actions served to provide Joe with an array of choices that he can make on a regular basis that both reinforce his separation from his childhood and solidify his membership as a worthy and contributing member of his rural community. For Joe, membership provides him with a certainty that he had successfully carved a different path for himself and is worthy of respect and dignity.

Other participants grew up in the context of loving and supportive families who taught them the value of belonging to a group. These participants knew how healthy groups operate and how various needs can be met by membership. Thus, they took actions to ensure their continued membership. For example, Charlie described two attentive parents who instilled in him the value of hard work and with whom he moved around the state of Texas following his father's construction job. He now works part-time earning just over $5,000/year in a job that provides him with continued opportunities to "be productive," "be useful," and "feel good" as Charlie recognized that his continued membership is contingent upon his continued contributions.

In addition to the intrinsic values ascribed to membership, membership was also instrumentally important because it provided access to social support from other community members when needed. When I asked Linda to describe what it was like to live in her community of about 350 people in a rural county in central Texas, she said,

> "you know everybody and you are related to most of them and ah it's ok…here you break down on the side of the road probably five people will stop before you figure out what's wrong. You know and not even – not all my cousins."

She went on to say,

> "some days when you hurt so much you can't move, you can't sit, you can't lay down, you know, and ah but you know, like I had problems I could call one of my cousins or [a friend] or nearly anybody else in the community and they would get somebody out. So, there's – there's ah even if you aren't actually related everybody in the area tries to help."

Similarly, Janie who works only part-time due to sequelae from a heart attack in 2014 described a friend who helps her maintain her business of cleaning cabins and recounted that in her rural community, people "work together in helping each other out."

Jennifer, the urban-dwelling study participant had been raised in a rural, Midwestern community. Because of her physical disability, Jennifer perceived several aspects of the urban environment as preferable to her rural hometown. For example, she has an extended network of friends who are also wheelchair users and with whom she can identify and share support. She is also employed full-time in a professional position that provides an accommodation of her working from home one day per week because of the fatigue that accompanies her disability. Living in an urban environment also allows Jennifer to live in an accessible duplex in a neighborhood with sidewalks and curb cuts. For Jennifer, the supports made available in the urban environment provide her with the capability to be independent and self-sufficient. However, she does not have the close connections with others that were evident amongst the rural-dwellers. This has resulted in

the sense that if she needs assistance with something, she must specifically *ask* for it. In contrast to the rural-dwelling participants who perceived that help would be freely given and received, Jennifer struggled to ask for help because she did not want to be perceived as weak, needy, or helpless.

For the rural-dwelling participants, membership conveyed a sense that the provision of social support was not charity or a handout but rather was an opportunity to share with others and to build a stronger community. Sharon, who was initially taken back by the mutuality of relationships in her rural community, said,

> "I was like, 'what? Y'all actually help people when it come to certain things.'" …It just – it just humbled me to see how some people in this community do for you. And they don't ask – they do it because they want to. Not because you owe me later, none of that."

Sharon said that she had been a recipient of others' generosity and also takes the opportunity to give back as she is able thereby demonstrating how membership in her rural community has transformed her and led to the internalization of values reflective of her role as a group member.

Group membership also allowed for reciprocation of the goodwill offered by others. Reciprocation was integral to both the maintenance of membership and for providing a sense of competence and purpose. Charlie described this process of reciprocation succinctly. I asked him why he spent so much time and effort engaged in work and volunteer activities when there were days that he couldn't walk due to his pain and mobility limitations. He said,

> "To give me the opportunity to give back. To help – because if you – the best way not to feel sorry for yourself is to help somebody else. That's the best cure. And it gives me that opportunity, um, it makes me feel necessary, fulfilled, uh, and there's some perks that come along with it. People appreciate what I do, and when they see me on the street, they tell me, and that makes me feel good."

Cathy shared a similar sentiment about why she spends her time engaged in various community activities:

> "I think when people are self-absorbed, and they can't think past themselves and their illnesses, if they just go to the nursing home, and walk around, and visit with these people, or go to the hospital, you know, and visit with somebody, or a shut-in, or something, it's – it's a rewarding feeling. …I enjoy it."

Cindy, on the other hand, has been unable to maintain her previous role as a contributing member to her rural community. Cindy, who was 50 years old at the time of our interview, was diagnosed with a progressive neuro-degenerative disease at age 43. She has struggled with the unpredictable nature of her illness, the limitations her illness has imposed, and her perceptions that others view her as a sad and tragic story without much to contribute to the community. She tearfully recounted how she "came home to do nothing" after her diagnosis. Thus, despite the fact that she had been a well-known small business owner and community volunteer for many years before her diagnosis, as her physical and social capacity declined, her social status changed thereby making membership more tenuous.

DISCUSSION

Previous work focusing on well-being among rural-dwelling, working-age adults with disabilities is limited in scope, and the findings from this study extend our understanding in a few key areas. First, findings of this study support a long-held assumption that relying upon models developed in urban or suburban areas is insufficient for adequately addressing the health care needs of rural dwellers (Long & Weinert, 1989; Gangeness, 2010; Pullen, Walker, & Fiandt, 2001; Stuifbergen, 1999). The findings from this study are unique, however, because they detail the social processes by which rural-dwelling adults with disabilities mobilize individual and collective resources in order to

overcome functional limitations and environmental barriers to establish group membership and create a sense of well-being.

At a time in our country when we are struggling to discover efficient and cost-effective approaches for providing long-term services and supports (LTSS) that maximize health and maintain respect for human dignity, this study provides a framework for the provision of such in rural areas. LTSS for the elderly and younger populations with disabilities represent a substantial component of national health care spending: $219.9 billion in 2012 (O'Shaughnessy, 2014). Forty-three percent of people receiving LTSS are between the ages of 18 and 64 (O'Shaughnessy, 2014), and demographic data indicate that the population of adults in need of LTSS is proportionately larger in rural versus urban areas (Rural Policy Research Institute, 2017). Thus, ensuring culturally-appropriate and person-centered interventions and policy solutions for adults living with disabilities in rural areas should be considered a priority amongst all stakeholders.

It has been argued that addressing the nation's LTSS needs will require a multi-pronged strategy that incorporates a range of health and social service needs (Naylor, Kurtzman, Miller, Nadash, & Fitzgerald, 2015). Others have similarly suggested that cross-sectoral collaborations are needed to improve health outcomes (e.g., Towe et al., 2016), and non-health care organizations are increasingly being recognized for their roles in meeting the interrelated social and health needs of a population (Brewster, Kunkel, Straker, & Curry, 2018). Findings from this research can facilitate the cross-sectoral collaborations needed to improve health outcomes (Towe et al., 2016) by providing a framework for primarily urban-based entities (such as Area Agencies on Aging, Centers for Independent Living, or Aging and Disability Resource Centers) to effectively reach and serve rural-dwelling populations.

In this study, participants indicated that they have an established social process that facilitates well-being; this process includes the reciprocal exchange of services in the context of living in a rural environment with a disability. It is suggested, therefore, that health care and other providers offering LTSS might seek to capitalize on the established social ecosystems within the rural community. For example, an important early step for service providers and policymakers working in rural areas would be to engage people with disabilities in community assessments, program development, and policy evaluation. Stakeholders could seek to establish relationships with rural community members living with a disability as well as traditional community gatekeepers such as church pastors. Tapping into these informal networks would yield insight as to how people with disabilities engage in the reciprocal exchange of services. Subsequently, formal community-based organizations could seek to reinforce and augment these established processes instead of seeking to disrupt what is already in place. Engagement in this manner could not only ensure inclusive and accessible programs and services but could also directly influence their well-being as it would provide an opportunity for social participation and contribution to the community.

This research also supports previous evidence regarding the utility of a social constructionist perspective to policy development (e.g., Harrison, 2006; Harrison et al., 2013). The extensive evidence regarding shortcomings of rural areas and the associated negative health implications (e.g., Davidsson & Södergård, 2016; Meit, et al., 2014) underscores the urgency of attention directed at rural health. However, this objectivist approach tends to identify problems and needs of rural areas from an outsider's perspective. Proposed solutions, therefore, frequently require outside professionals' assistance and overlook the potential of the local communities and citizens to create and sustain health and well-being (Morgan & Ziglio, 2007). The knowledge constructed

between the researcher and the participants in this study painted a nuanced picture of the history, culture, social relations, and enduring ties to the land that were identified as significant influences on well-being. Capitalizing on the meanings of these important cultural artifacts and on the strengths and assets of rural areas could, therefore, yield interventions and policies that are more culturally appropriate. For example, many people, including those with disabilities, choose to live in rural areas because they value the quiet, calm, and more relaxed environment and appreciate a connection with nature and the physical environment. Service providers should seek to capitalize on these unique aspects of rural areas that contribute to well-being of people with disabilities. Convening a regular walking group at a local park or a town square for people with disabilities—even those who may use a wheelchair or electric scooter for mobility—could serve as a source of social interaction, exercise, and connection with the outdoors.

Previous literature regarding social support among adults with disabilities in the rural context is mixed. Social support refers both to the emotionally-sustaining and instrumentally-beneficial qualities of social relationships (Umberson & Montez, 2010) and is consistently identified as a critical factor for maintaining health and quality of life for people with disabilities. Some evidence indicates that satisfaction with support is greater in rural adults with disabilities (McPhedran, 2011) while other research supports the notion that social support is more limited among rural-dwellers with disabilities (Danzl et al., 2013; Goodridge et al., 2015). Findings from the current study indicate that social support is a component and an outcome of membership and it is the acquisition and maintenance of membership status within the specific rural community that is important for well-being. Membership, however, extends beyond the receipt of social support. This is consistent with work that holds that meaningful connection to others forms a central focus through which psychological, symbolic, social, and material goods are distributed

and needs are met (White, 2017). Thus, findings from this study indicate that it may not be the quantity of social support that is important, but rather the interpretation of being a member of a group and belonging to a network of reciprocity that is fundamental. The rural participants understood that they required support and assistance from various others to overcome barriers and engage in meaningful activities; well-being emerged from confidence in knowing that there would be someone or some cause to which they could lend support in the future. To the extent that participants did not have confidence that they would be able to fulfill their membership obligation of reciprocation, well-being was lessened. Further, opportunities for interaction with peers are more limited in rural than in urban areas. Findings from this study indicate that peer support groups may be an important source of social engagement for people with disabilities in rural areas. Therefore, an important implication for further research is to test the acceptability and feasibility of virtual peer support groups. Additionally, existing community-based organizations could consider developing partnerships with urban-based or other rural-based entities to ensure that peer support groups are available for people with disabilities.

Findings from this study also support previous arguments that quantitative measurements regarding the hours per day spent in an activity are insufficient for capturing the meaning or quality of participation or the level of engagement in the activity (Barclay, McDonald, & Lentin, 2015; Hammel et al., 2008). In this study, participants valued the ability to choose from among an array of options and to feel empowered to choose to *not* participate in particular activities. While health benefits may be associated with a particular course of action, the ability and act of choosing to participate (or not) is itself important for well-being. This finding is consistent with prior research that found that decisional autonomy and self-determination is frequently more important than the ability to independently perform activities by oneself (Cardol, de Jong,

& Ward, 2002; Harrison, Umberson, Lin, & Cheng, 2010). It is also in keeping with the capabilities approach as formulated by Sen (1992) who contended that the ability to choose between meaningful options is itself a valuable part of living, and a life with meaningful choice can be considered to be of higher quality.

Finally, findings support the somewhat counterintuitive yet widely endorsed notion that objective life circumstances such as income or educational level frequently do not predict a person's subjective sense of well-being (Easterlin, 1995; Ryan & Deci, 2001). None of the participants in this study was wealthy, and many were objectively poor. However, well-being was related to the ability to live in community with others as part of a collective and in accordance with personal values. Prior research has indicated that a positive sense of well-being is not related to an individual's values per se but to an individual's success in attaining whatever it is that he or she values (Diener & Suh, 2000). Further, congruence between an individual's values and his or her sociocultural environment has been found to promote well-being regardless of the particular values to which people ascribe importance (Sagiv & Schwartz, 2000). Participants in this study identified several values that were important to them. Likely, the values that were identified were not an all-inclusive list and other individuals in rural areas may identify different or additional value priorities. However, the extent to which participants in this study were able to live in accordance with and to share values with the larger community predicted the development of a rural attitude and the extent to which people chose to participate in various activities. Not all individuals who live in rural areas have or develop a rural attitude, and it is theorized that the lack of such would preclude membership in the rural community.

LIMITATIONS

There are important limitations to this study that should be considered. First, the findings of this study are limited to the rural-dwelling individuals who participated in this study and are not generalizable to a broader audience. However, detailed descriptions of the sample were included to aid in transferability. Further, this study was limited because of the small sample size and the lack of diversity within the sample. While there was one African-American participant and one participant who identified as part Native American, the sample was primarily white. Additionally, people currently living in institutional settings were not included as part of this sample, but their experiences would yield important insights as to the distinctive influences that rural may have on well-being. It is suggested that further research is needed with individuals from various living contexts; class backgrounds; and racial, ethnic, and sexual identity groups in order to fully reflect the diversity of experience of disability in rural America. Further, the rural participants in this study all subscribed to a rural attitude which facilitated their membership and sense of well-being. Not all persons who live in rural areas would adhere to a rural attitude, so it is suggested that further research investigate mechanisms by which those individuals pursue well-being. Data were collected over a short period of time (7 months) and therefore do not represent well-being across the disablement trajectory of these participants. However, participants were diverse in terms of functional abilities and life histories which provided nuance and dimensionality to the theoretical concepts. Future studies could incorporate a life course approach to rural-dwelling adults with disabilities in order to provide a framework for examining how the rural environment interacts with earlier life experiences to shape membership and participation opportunities and, thus, well-being.

CONCLUSION

In conclusion, this study found that membership in the rural community provided access to the material and psychological support needed to secure a sense of well-being. Establishing and maintaining membership was a dynamic process involving ongoing appraisals of abilities, desires, opportunities, and demands as well as the extent to which these fit with personal values. Strategic participation occurred due to personal choice (e.g., the person values an activity or anticipated outcome, the person does not believe the activity to be worth the effort) and/or environmental factors (e.g., lack of accommodating employment opportunities, inaccessible restrooms). Ultimately, strategic participation and membership often hinged upon the possibility of living out personal and shared values such as being hard-working, dependable, and trustworthy in connection with the rural landscape.

This study is unique in that it advances our understanding of the importance of context and space to rural adults with disabilities. It is limited to the experiences of the participants in this study, but overall, well-being can be thought of as an embodied individual and collective experience resulting from the ongoing process of membership. It is through membership that individuals were able to have emotional and material needs satisfied, engage in meaningful social relationships, and strengthen self-confidence and self-valuing. Indeed, it has been suggested that a relational conception of well-being such as that identified in this study can increase sensitivity to difference by allowing a dialogue and debate about what people value (Bache, Reardon, & Anand, 2015). Approaches to pursuing and securing wellbeing such as identified here do not necessarily promise objective health improvement for individuals. They may, however, provide the stimulus to refocus research and policy attention onto the meanings and contexts of individual and shared experiences. Ultimately, a nuanced understanding of well-being

such as identified in this study can facilitate thinking among healthcare practitioners and policymakers about how life can be made better for individuals and the communities in which they live.

Chapter 5. Summary, Conclusions, & Recommendations

This chapter summarizes this dissertation, provides conclusions, and makes recommendations for future research. Specifically, an overview of the overall purpose of the project will be provided. Next, the research questions, methodologies, data analysis techniques, and findings for each study are reviewed. Following this, conclusions and recommendations for future research, nursing practice, and health policy are outlined.

SUMMARY

The purpose of this dissertation research was to identify and provide theoretical justification for mechanisms by which sociocultural factors contribute to health and social disparities. Myriad evidence documents systematic disadvantages and disparate health outcomes between social groups based on race (e.g., Williams, 2012; Xu, Kochanek, Murphy, & Tejada-Vera, 2010), disability status (e.g., Dixon-Ibarra & Horner-Johnson, 2014; Stevens et al., 2016), and rural residence (e.g., Meit et al., 2014; Singh & Siapush, 2014). The premise of this dissertation was that the pervasive disparities in health and well-being experienced by individuals in these groups contradict ethical principles such as respect for equal moral worth of all (Nussbaum, 2006; Yamin, 2009) and important social values such as non-discrimination (Braveman & Gruskin, 2003). The disparities have also created an unsustainable burden on our nation's healthcare system: estimates of the economic burden of health disparities run into the trillions of dollars in direct medical expenditures and indirect social costs (LaViest, Gaskin, & Richard, 2011).

A social constructionist perspective situated in a capabilities approach (Sen, 1992; 1999) facilitated an understanding of the socially embedded nature of individuals and

called attention to how social, cultural, and economic conditions influence people's opportunities, choices, health, and, ultimately, well-being. Specifically, this research has yielded insights as to how, when, and why social context may influence patient decision-making, healthcare utilization, and the processes used in the pursuit and maintenance of well-being. Each study will be summarized in turn below, but taken together, the findings from this research underscore the critical notion that individuals are inextricable from the social worlds they inhabit. The meanings that people ascribe to health, health care, well-being, and disability combined with individual ability within specific sociocultural contexts should be considered by nurses at all levels in order to provide holistic, person-centered, and culturally-relevant care. Without a holistic assessment of an individual's social, cultural, and economic circumstances, health care providers may inadvertently perpetuate disparities by providing culturally inappropriate care and/or prescribing physically or economically unattainable interventions.

CHAPTER TWO

The purpose of this chapter was to clearly position disparities in health and well-being experienced by adults with disabilities as a matter of equity and social justice requiring action on wider social determinants operating outside of the healthcare system. This chapter drew upon literature regarding mainstream cultural values influencing the meanings of disability and well-being and highlighted philosophical positions related to health policy. This chapter also incorporated evidence regarding the extent to which the World Health Organization's *International Classification of Functioning, Disability, and Health* (ICF; 2001) accommodates the diverse experiences, values, and needs of people with disabilities. It then synthesized results from Chapters Three and Four and presented conclusions in a concise issue brief.

Findings from both Chapters Three and Four underscored the importance of recognizing that participation in community life is a subjective experience that is given meaning through choice, and that choices are facilitated or constrained through social, economic, and cultural contexts. Specifically, this brief presents evidence suggesting that the sociocultural environment influences individual values and, consequently, preferences and decision-making. Further, this brief argues that autonomy and personal agency are frequently constrained by socioeconomic factors and practical access barriers.

In this dissertation, Chapter Three identified that African American and white veterans accessing care through the VHA differed in their willingness and choice to undergo a potentially effective surgical intervention for a disabling condition. Chapter Four found that people with disabilities living in rural areas had established social processes to participate in a network of reciprocity in order to secure access to needed supports and achieve a sense of well-being. Thus, this issue brief presented an argument that while the ICF is well-intentioned in its effort to see people with disabilities as fully autonomous and capable individuals rather than emphasizing impairment or medical deficiency, it does not adequately consider the contextual nature of life with a disability. The capabilities approach was then proposed as a useful alternative for conceptualizing social participation and functioning. The issue brief concluded by reinforcing the historical roots of nursing practice in social justice and population health and suggesting ways by which nurses can best contribute to social justice for adults with disabilities.

CHAPTER THREE

The purpose of this study was to provide a justification for this dissertation's theoretical framework, which asserts that differing social circumstances result in disparate levels of the social, economic, and cultural capital (Bourdieu, 1986) needed to

convert health resources into a sense of well-being. This study was a critical analysis of evidence from the Veterans Healthcare Administration (VHA) documenting racial disparities in health care utilization and outcomes among veterans with osteoarthritis—a potentially disabling condition for which there is an effective surgical treatment. Evidence from the VHA was chosen because the VHA is a health care system intended to provide care to veterans with similar socioeconomic backgrounds from all racial groups. As such, the VHA serves as its own control for the potential confounders of insurance status or unequal access to care (Washington, Villa, Brown, Damron-Rodriguez, & Harada, 2005).

This study reviewed empirical evidence that documented differences in total joint arthroplasty utilization and outcomes between African American and white patients in the VHA. It then reviewed existing literature that offered patient-, provider-, and system-level factors as potential explanations for the disparities. Upon critical analysis, it was found that underlying reasons for these factors had not been explored, and a closer examination yielded insight into the socially-situated origins of these factors. Thus, a theoretical explanation linking Bourdieu's (1986) concepts of capital interaction and habitus with Sen's (1992) capabilities approach was outlined. This study concluded with a detailed examination of the applicability of the capabilities approach for addressing health disparities in the United States.

CHAPTER FOUR

Chapter Four presented results from a constructivist grounded theory study, the purpose of which was to construct a substantive theory to explain how adults with disabilities living in rural counties in Texas define and pursue well-being. Findings from the critical analysis of racial disparities in the VHA reinforced the assumptions that

health should be viewed as a means to the end of well-being and, therefore, that myriad and complex factors beyond the traditional healthcare system influence both health and well-being. This qualitative study of working-age adults between the ages of 35 and 70 years living in a Texas county with less than 10,000 residents stemmed from these assumptions and from the significant gap in knowledge related to the well-being of working-age adults living with disability in rural America. All of the adults who participated in this study self-reported ambulatory and/or hearing impairments. It was the intention of the researcher to understand well-being from the perspective of rural-dwelling adults with disabilities along with the social processes involved in creating and pursuing well-being amongst this population. Ultimately, working with her analytic team, the researcher developed a model of well-being in rural-dwelling adults with disabilities that considers the influence and importance of the rural sociocultural environment.

Thirteen individuals, 12 rural-dwelling and one urban-dwelling (nine women and four men) were interviewed one to three times each over a 7-month period for a total of 20 interviews that lasted between 1.5 and three hours each. In order to answer the research questions, the study utilized open-ended interview questions asking when and how the participant's initial impairment occurred, how the impairment had affected the participant's life over time, and what the participant enjoyed doing. Participants were also asked to discuss both positive and negative qualities of their rural communities, to describe people with whom they interact on a regular basis, and to explain their typical daily routines, as well as whether and how their disability affected those relationships and routines. In addition to face-to-face interviews with participants, the researcher wrote field notes and collected standardized data regarding demographics and well-being via a demographic questionnaire, the Kessler-6 Psychological Distress Scale (Kessler et al., 2003), and the ICECAP-A (Al-Janabi, Flynn, & Coast, 2011).

The constant comparative method of data analysis (Strauss & Corbin, 1998) focused on understanding the meanings, intentions, and actions of the study participants. Tenets from symbolic interactionism (SI; Blumer, 1969) and from Amartya Sen's capabilities approach (1992) were used as a sensitizing framework to structure the data collection and analysis in order to gain an understanding of well-being and the processes used to pursue well-being. Using this combination of concepts as a sensitizing framework facilitated an understanding of the processes by which individuals in this population are empowered to make decisions about important aspects of their life, how they convert their resources into valued outcomes and activities (e.g., working, participating in social activities, being healthy), and how they assign meaning to and place value on particular outcomes. It also facilitated an examination of the preconditions necessary for human agency as well as the meanings associated with various actions (or inactions). Categories and subcategories that identified the processes used to define and pursue well-being were described and ultimately related to the core category of *membership* that explained the most variation in the data.

Findings indicated that for these participants, well-being is situated, relational, and dynamic. That is, rather than a set state to be achieved and then enjoyed, well-being is emergent and facilitated over time through the interaction between personal, cultural, and environmental structures and processes. The definition constructed by the researcher and participants indicated that well-being is a *process* of seeking and maintaining membership in the rural community thereby cultivating intricate connections with others in accordance with shared history and personal values and to the fullest extent of one's abilities. Membership facilitated access to the social, psychological, and material supports needed to perform important social roles (such as grandmother, community

volunteer, rancher or church member) and to overcome barriers (such as difficult terrain or financial hardship).

An important strength of this study was the inclusion of an urban-dwelling participant. This participant served as a 'negative case' whereby I could test the boundaries of the developing theory. For this participant, the access to institutional supports (such as an accessible and accommodating working environment) and infrastructure (such as sidewalks with curb cuts) in the urban environment provided her the ability to maintain independence, overcome environmental barriers, and perform social roles. She did not need to rely on the collective for the pursuit of well-being; indeed, she reported avoiding asking for support from others in order to avoid the appearance of being weak, needy, or dependent. Thus, findings from this study support the long-held assumption that models developed in urban or suburban areas are insufficient for addressing the needs of rural-dwellers (Gangeness, 2010; Long & Weinert, 1989; Pullen, Walker, & Fiandt, 2001; Stuifbergen, 1999), and nurses working in rural environments should consider tapping into the distinctive social ecosystems of those communities.

DISCUSSION AND IMPLICATIONS FOR RESEARCH, POLICY, AND PRACTICE

An interesting moral question arises when considering the implications of this dissertation: how can nurses best contribute to the pursuit of the ethical goal of recognizing the full, complex personhood of people from diverse backgrounds with differing abilities on the one hand while still honoring their lived experiences and developing pragmatic policies to improve their health outcomes on the other hand? For example, how do we move beyond negative stereotypes about the desirability of "normal" physical or cognitive ability while still acknowledging the reality that many

impairments are painful and choice-limiting? Further, how do we consider the cultural and personal values that give meaning to individual lives and develop policy and practice that reflect a sensitivity to particular circumstances? This dissertation suggests the use of the capabilities approach (Sen, 1992) as a normative framework that can assist in this process.

The capabilities approach has been widely used in the fields of human development and economics (e.g., Lorgelly, 2015; Mitchell, Roberts, Barton, & Coast, 2015; Muffels & Headey, 2013), disability studies (e.g., Burchardt, 2004; Mitra, 2006; Venkatapuram, 2014), and education (e.g., Terzi, 2005; Walker, 2012). However, it has not yet been widely implemented within the field of nursing. This dissertation suggests that the capabilities approach can be operationalized in pragmatic ways for a practice discipline such as nursing. Research is needed, however, to further refine this framework and adapt it in a way that makes it increasingly sensitive to the specifics of nursing practice for people with disabilities. For example, the capabilities approach as developed by Sen (1992) is deliberately incomplete. That is, he is insistent that one pre-determined list of capabilities relevant for all cultures in all contexts is not possible (nor is it desirable). Thus, identifying and valuing relevant capabilities for specific contexts is needed. However, Sen advocates for a participatory approach to identifying capabilities as he considers reasoned agreement an "important foundational quality central to political and social ethics" (Sen, 1992, p. 48). This dissertation is an initial step towards identifying valued capabilities amongst rural-dwelling, working-age adults with disabilities as well as the social processes involved in converting capabilities into well-being.

The findings related to rural-dwelling adults with disabilities are particularly salient as researchers, policymakers, and healthcare providers continue to seek efficient

and cost-effective approaches for providing long-term services and supports (LTSS) that maximize health and maintain respect for human dignity. Forty-three percent of people receiving LTSS are between the ages of 18 and 64 (O'Shaughnessy, 2014), and it has been argued that addressing the nation's LTSS needs will required a multi-pronged strategy that incorporates a range of health and social service needs (Naylor, Kurtzman, Miller, Nadash, & Fitzgerald, 2015). Others have similarly suggested that cross-sectoral collaborations are needed to improve health outcomes (Towe et al., 2016). Indeed, non-health care organizations are increasingly being recognized for their roles in meeting the interrelated social and health needs of a population (Brewster, Kunkel, Straker, & Curry, 2018).

Examples of community-based organizations that serve rural communities in the U.S. are Centers for Independent Living (CILs), Area Agencies on Aging (AAAs), and Aging and Disability Resource Centers (ADRCs). These organizations are federally-mandated but independently run in order to be flexible and responsive to local communities' needs. However, many of these organizations are based in urban areas and are limited in their understanding of how to best reach and serve rural-dwelling populations. Therefore, findings from this research can help these organizations better understand how rural-dwelling individuals mobilize individual and collective resources in order to overcome functional limitations and environmental barriers and participate in their social networks. This understanding can help to maximize these important, albeit limited, community resources. Future studies with larger and more diverse samples of rural-dwelling adults should seek to further refine the model of well-being developed in this study and to identify how conversion factors may differ across time and space.

Another question arises when considering the findings of this research: is well-being an appropriate evaluative outcome for healthcare policy and practice? Many

healthcare policies are geared towards helping individuals maintain independence and perform social roles, and the programs and interventions developed in response to these policies have benefits that extend beyond individual clinical outcomes. For example, programs that fall under the umbrella of LTSS focus on a broad range of supportive services needed by people who are limited in their ability for self-care due to a physical, cognitive, or mental disability or condition but specifically exclude medical and nursing services that are needed to manage any underlying health condition that may have led to disability (O'Shaughnessy, 2014). Thus, it stands to reason that capturing the broad spectrum of benefits accrued requires attention to indicators beyond clinical outcomes. Findings from this dissertation support the notion that investigating well-being can provide a more complete and detailed rendering of individual lives than does the traditional reliance on biomedical clinical indicators. This supports previous calls for measuring well-being in order to capture the benefits of a diverse range of health and social policies (Al-Janabi, Flynn, & Coast, 2012). Inherent in this argument for shifting to well-being as an outcome measure is a claim that health should be recognized as a determinant of well-being and that people seek health as a *means* to participate in valued and meaningful activities. For people with disabilities who may never attain so-called 'normal' ability or health status, a shift to well-being could accommodate the broad array of interventions and the multidisciplinary approach needed to combine clinical treatment with attention to policy and social environments.

While this dissertation supports the inclusion of well-being as an evaluative outcome for policy and practice, it does so with the caveat that this inclusion be carried out in accordance with the capabilities approach. Further, this researcher does not claim that well-being be investigated to the exclusion of other outcomes such as health status, functional ability, income, or educational level. That is, this dissertation's findings do not

suggest that policy or practice should focus on life satisfaction, preference fulfillment, or personal meaning to the exclusion of external social factors (such as discrimination) or environmental barriers (such as inaccessible buildings). Rather, findings support the notion that well-being should be defined in terms of what a person can do and be in their life in order to capture the overlapping influences of personal values, health status, cultural meanings, social context, and environmental barriers. Indeed, the findings of this dissertation underscore the inextricably linked nature of individuals and their sociocultural environment. This definition of well-being therefore avoids an implicit message that low levels of well-being should be attributed to poor coping strategies or to some type of personal failure. Further research is needed to determine how to best operationalize well-being in accordance with the capabilities approach in order to identify how individuals with from diverse backgrounds and with differing levels of functional ability can be enabled and empowered to achieve valued functionings.

A third question arising from this dissertation is how to best facilitate efficient and effective multi-level interventions within the dominant biomedical paradigm in which we practice. If we recognize the importance of social context, culture, and environmental barriers to health outcomes, then we should encourage the nursing discipline to become more capacious and inclusive of interventions beyond those prescribed in traditional medical models. To date, however, approaches to nursing care for people living with long-term conditions that incorporate attention to individual-level factors (such as personal knowledge and skills) with attention to psychosocial and socioeconomic circumstances are more evident in theory than in practice. This narrow focus has been attributed to a disease-focused orientation on helping people manage conditions in biomedical or disease-control terms, an orientation that has limited medical practitioners' ability to consider what matters in people's lives and how people can be

supported in shaping their own lives (Morgan et al., 2016). A narrow focus on biomedical or disease-control terms is too limiting for many people, however. As Harrison and Stuifbergen (2006) argued, purpose in life is essential: "some impairment cannot be cured; therefore, ways to promote quality of life are needed, which is where many nurses can focus attention" (p. 153).

Identifying meaningful activities and supporting individuals with disabilities to engage in those activities is key to supporting their pursuit of a purposeful life. Identifying these activities can also refocus attention on the importance of autonomy, self-determination, and human agency. Care must be taken, however, to recognize that respecting autonomy is not equivalent to defending an individual's freedom to be left alone (Knight, 2016). Neither is an observance of an individual's social participation indicative of the meaningfulness of that activity or of its congruence with the underlying purpose of the individual's life. Thus, nurses must facilitate a shared deliberation between patients, families, and communities as to what is meaningful and worth pursuing. To the extent that support is needed for individuals to pursue those opportunities, nurses must be attentive to securing the needed support, whether through direct care provision, program development, or policy solutions.

A final question stemming from the findings of this dissertation centers on the importance of informal social relationships with healthcare providers to the healthcare experiences of people with disabilities. A somewhat surprising finding arising from Chapter Four was the general level of satisfaction with rural healthcare services reported by the participants. Participants recognized that accessing specialty care was challenging, and some participants shared specific examples of clinical policies contradicting their lived experiences. However, the informal social relationships participants enjoyed with their rural healthcare providers contributed to feelings of satisfaction with care and,

ultimately, to well-being. This finding invites further investigation of the mechanisms by which informal social relationships between rural-dwelling adults with disabilities and healthcare providers influence satisfaction with care. One possibility is that these relationships contributed to increased accessibility to healthcare providers in informal settings. Another possibility is that the formation of relationships with people with disabilities outside of the patient role served to sensitize providers to the humanity and dignity of these individuals, thereby allowing the providers to move beyond the all-too-common tendency to reduce individuals with disabilities to their disability. Additionally, this finding could yield further insight into the disparities identified between African-American and white veterans accessing care within the VHA. While empirical evidence clearly supports the conclusion that inequitable levels of social, economic, and cultural capital influence disparities in healthcare utilization and outcomes, it is plausible that relationships with healthcare providers also influence patient decision-making. Thus, this finding warrants further investigation.

CONCLUSION

In conclusion, this dissertation used a social constructionist perspective of well-being situated within a capabilities approach (Sen, 1992; 1999) to explore health disparities. Taken together, findings advance our understanding of the mechanisms by which sociocultural factors influence well-being among African Americans with osteoarthritis, rural residents, and adults with disabilities as well as how these factors contribute to disparities in well-being. Ultimately, a theoretical understanding of the meanings of health, health care, well-being, disability, and health disparities such as explored in this study, can facilitate thinking among healthcare practitioners and

policymakers about how life can be made better for individuals and the communities in which they live.

Tables and Figures

Table 1. Summary of Disability Data Sources

Data Source	Survey Notes	Measure of Disability
National Health Interview Survey (NHIS)	Cross-sectional household interview survey; sampling and interviewing are continuous throughout the year.	Answer of "yes" to any of the following six questions: • Are you deaf or do you have serious difficulty hearing? • Are you blind or do you have serious difficulty seeing, even when wearing glasses? • Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? • Do you have serious difficulty walking or climbing stairs? • Do you have difficulty dressing or bathing? • Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?
Current Population Survey (CPS)	Monthly survey of about 60,000 eligible households that provides information on the labor force status, demographics, and other characteristics of the nation's civilian non-institutional population age 16 and over.	Persons are classified as having a disability if there is a response of "yes" to any of the following questions for household members who are 15 years and older: • Is anyone deaf or does anyone have serious difficulty hearing? • Is anyone blind or does anyone have serious difficulty seeing, even when wearing glasses? • Because of a physical, mental, or emotional condition, does anyone have serious difficulty concentrating, remembering, or making decisions? • Does anyone have serious difficulty walking or climbing stairs? • Does anyone have difficulty dressing or bathing? • Because of a physical, mental, or emotional condition, does anyone have difficulty doing errands alone such as visiting a doctor's office or shopping?

Table 1. Continued

American Community Survey (ACS)	Series of monthly samples to produce annually updated estimates for the same small areas	Respondents who report any one of the six disability types are considered to have a disability: • Hearing difficulty – deaf or have serious difficulty hearing • Vision difficulty – blind or have serious difficulty seeing, even when wearing glasses • Cognitive difficulty – because of a physical, mental, or emotional problem, have difficulty remembering, concentrating, or making decisions • Ambulatory difficulty – having serious difficulty walking or climbing stairs • Self-care difficulty – having difficulty bathing or dressing • Independent living difficulty – because of a physical, mental, or emotional problem, have difficulty doing errands alone such as visiting a doctor's office or shopping
North Carolina Behavioral Risk Factor Surveillance Survey (BRFSS)	The BRFSS is a random telephone survey of adults designed to collect information about health status, health behaviors, and use of health services related to the leading causes of illness and death. States have the option of customizing some questions and modules.	Disability status is determined by a "yes" response to one or more of the following four questions: • Are you limited in any way in any activities because of physical, mental, or emotional problems? • Do you now have any health problem that requires you to use special equipment such as a cane, a wheelchair, a special bed, or a special telephone? • A disability can be physical, mental, emotional, or communication related. Do you consider yourself to have a disability? • Because of any impairment or health problem, do you have any trouble learning, remember, or concentrating?
National BRFSS	The BRFSS is a random telephone survey of adults designed to collect information about health status, health behaviors, and use of health	Disability status is determined by a "yes" response to one or both of the following questions: • Are you limited in any way in any activities because of physical, mental, or emotional problems? • Do you now have any health problem that requires you to use

Table 1. Continued

	services related to the leading causes of illness and death.	special equipment such as a cane, a wheelchair, a special bed, or a special telephone?
Medical Expenditures Panel Survey (MEPS)	The MEPS annual survey provides a nationally representative sample of the health care utilization and expenditures of U.S. families and individuals, their medical providers, and employers. It is a subsample of respondents from the previous year's NHIS.	Cognitive limitations: • Anyone who experiences confusion or memory loss, has problems making decisions, or requires supervision for their own safety. Physical disability: • Does anyone in the family have difficulties walking, climbing stairs, grasping objects, reaching overhead, lifting, bending or stooping, or standing for long periods of time? • Does anyone in the family use any assistive devices (aids or special equipment)?

Table 2. Participant Demographics

Participant Name[a]	Age	Gender	Race/Ethnicity	Type of Impairment[b] (age at onset)	Length of Time living in County of Residence (Rural/Urban)	Marital Status	Educational Level	Employment Status
Charlie	66	M	Non-Hispanic, White	Osteoarthritis, chronic low back pain (59)	26 years (Rural)	Married	High School	Part-time
Joe	56	M	Non-Hispanic, White	Osteoarthritis, chronic pain (47)	25 years (Rural)	Widowed	Associate's Degree	Part-time
Cindy	50	F	Non-Hispanic, White	Degenerative neurological condition (43)	19 years (Rural)	Married	High School	Unemployed
Bryan	55	M	Non-Hispanic, White	Multiple sclerosis, rheumatoid arthritis (33)	3 years (Rural)	Married	Master's Degree	Full-time
Debbie	66	F	Non-Hispanic, White	Early-onset hearing impairment (27)	15 years (Rural)	Married	Master's Degree	Part-time
Misty	66	F	Non-Hispanic, White	Paraplegia (4)	34 years (Rural)	Widowed	Bachelor's Degree	Self-employed

Table 2. Continued

Linda	70	F	White/Native American	Mobility limitations and chronic pain r/t car accident (38)	32 years (Rural)	Married	Bachelor's Degree	Retired
Janie	56	F	Non-Hispanic, White	Physical limitations r/t heart disease (53)	13 years (Rural)	Married	High School	Self-employed
Robert	70	M	Non-Hispanic, White	Hearing impairment; PTSD (18)	20 years (Rural)	Divorced	Master's degree	Retired
Katherine	56	F	Non-Hispanic, White	Osteoarthritis; bipolar disorder; PTSD (50)	12 years (Rural)	Married	High School	Unemployed
Cathy	70	F	Non-Hispanic, White	Hearing impairment (55)	43 years (Rural)	Married	College Degree	Retired
Sharon	44	F	African American	Multiple chronic physical and mental health conditions (37)	20 years (Rural)	Single	High School	Unemployed
Jennifer	35	F	Non-Hispanic, White	Paraplegia (18)	7 years (Urban)	Single	Master's Degree	Full-time

[a] All names are pseudonyms.
[b] Some identifying diagnoses are altered.

Table 3. Rural County Data

County	Population	Disability[a] Rate	% 35-64 years	COG region	Health Service Region
County A	5,240	17.2	35.7	23	7
County B	4,719	16.3	34.9	23	7
County C	10,611[b]	16.6	44.8	12	7
County D	4,427	18.1	39.5	10	9/10
County E	3,223	16.4	42.2	24	8

Notes. [a]Disability defined as functional limitation and answer to "yes" of one or more the American Community Survey questions regarding disability. [b] County classified as non-core according to Office of Management and Budget. COG = Council of Governments

Figure 1. Map of Urban-Rural Counties in the United States

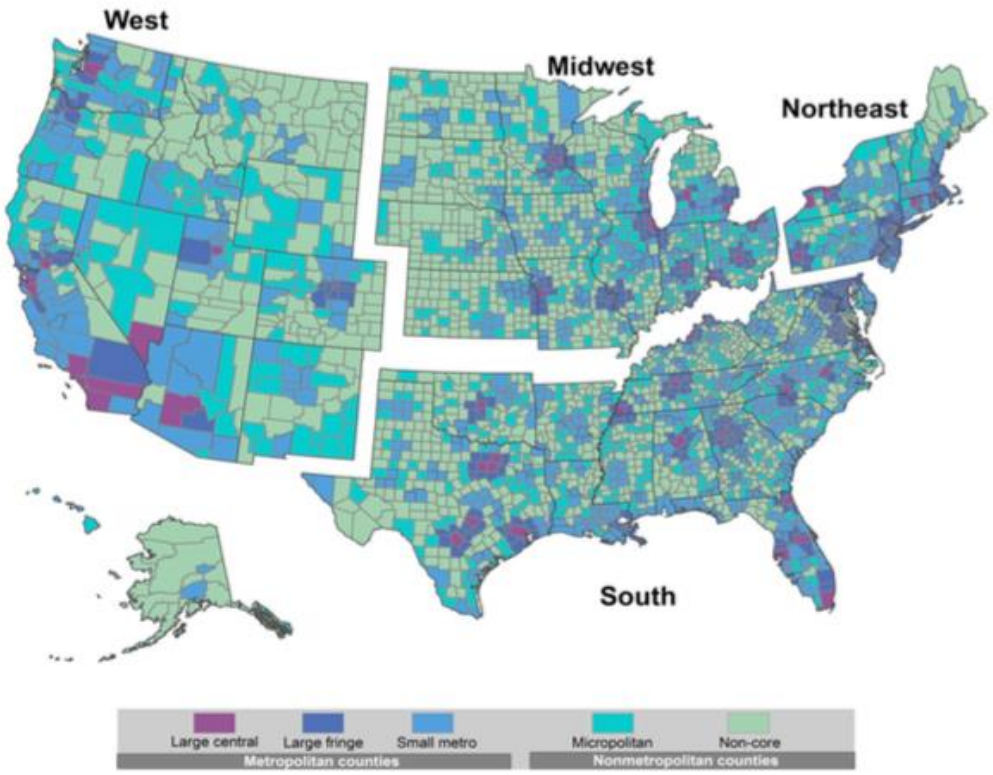
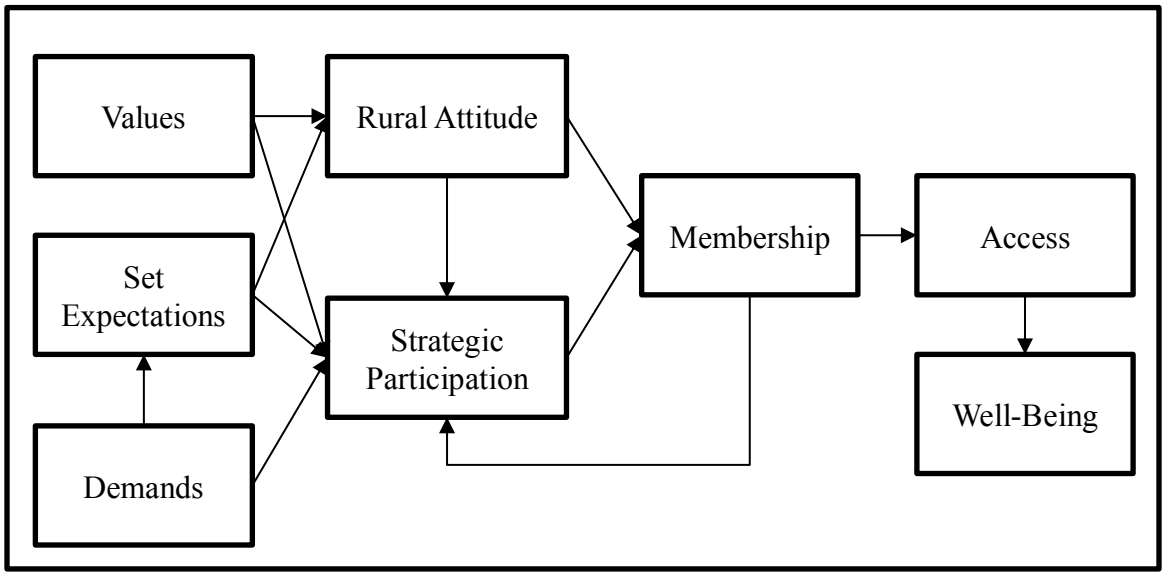


Figure 2. Model of Well-Being



Appendix A. Institutional Review Board Materials

OFFICE OF RESEARCH SUPPORT

THE UNIVERSITY OF TEXAS AT AUSTIN

P.O. Box 7426, Austin, Texas 78713 - Mail Code A3200
(512) 471-8871 - FAX (512) 471-8873

FWA # 00002030

Date: 11/08/16

PI: Tracie C Harrison

Dept: Nursing

Title: Basic Capabilities in Disability

Re: IRB Exempt Determination for Protocol Number 2016-08-0079

Dear Tracie C Harrison:

Recognition of Exempt status based on 45 CFR 46.101(b)(2).

Qualifying Period: 11/08/2016 to 11/07/2019. *Expires 12 a.m. [midnight] of this date.*
A continuing review report must be submitted in three years if the research is ongoing.

Responsibilities of the Principal Investigator:

Research that is determined to be Exempt from Institutional Review Board (IRB) review is not exempt from ensuring protection of human subjects. The Principal Investigator (PI) is responsible for the following throughout the conduct of the research study:

1. Assuring that all investigators and co-principal investigators are trained in the ethical principles, relevant federal regulations, and institutional policies governing human subject research.

2. Disclosing to the subjects that the activities involve research and that participation is voluntary during the informed consent process.

3. Providing subjects with pertinent information (e.g., risks and benefits, contact information for investigators and ORS) and ensuring that human subjects will voluntarily consent to participate in the research when appropriate (e.g., surveys, interviews).

4. Assuring the subjects will be selected equitably, so that the risks and benefits of the research are justly distributed.

5. Assuring that the IRB will be immediately informed of any information or unanticipated problems that may increase the risk to the subjects and cause the category of review to be reclassified to expedited or full board review.

6. Assuring that the IRB will be immediately informed of any complaints from subjects regarding their risks and benefits.

7. Assuring that the privacy of the subjects and the confidentiality of the research data will be maintained appropriately to ensure minimal risks to subjects.

8. Reporting, by submission of an amendment request, any changes in the research study that alter the level of risk to subjects.

These criteria are specified in the PI Assurance Statement that was signed before determination of exempt status was granted. The PI's signature acknowledges that they understand and accept these conditions. Refer to the Office of Research Support (ORS) website www.utexas.edu/irb for specific information on training, voluntary informed consent, privacy, and how to notify the IRB of unanticipated problems.

1. Closure: Upon completion of the research study, a Closure Report must be submitted to the ORS.

2. Unanticipated Problems: Any unanticipated problems or complaints must be reported to the IRB/ORS immediately. Further information concerning unanticipated problems can be found in the IRB Policies and Procedure Manual.

3. Continuing Review: A Continuing Review Report must be submitted if the study will continue beyond the three year qualifying period.

4. Amendments: Modifications that affect the exempt category or the criteria for exempt determination must be submitted as an amendment. Investigators are strongly encouraged to contact the IRB Program Coordinator(s) to describe any changes prior to submitting an amendment. The IRB Program Coordinator(s) can help investigators determine if a formal amendment is necessary or if the modification does not require a formal amendment process.

If you have any questions contact the ORS by phone at (512) 471-8871 or via e-mail at orsc@uts.cc.utexas.edu.

Sincerely,

James P. Wilson

James Wilson, Ph.D.
Institutional Review Board Chair

2016-08-0079 Exempt Amendment Application - Acknowledged

1 message

Hammock, Meghan A <mhammock@austin.utexas.edu> Wed, Apr 5, 2017 at 8:32 AM
To: "Harrison, Tracie C" <tharrison@mail.nur.utexas.edu>
Cc: "whitney.monge@gmail.com" <whitney.monge@gmail.com>

RE: Well-being of adults with disabilities living in rural Texas: A grounded theory

Dear Tracie C. Harrison,

Thank you for notifying our office of the changes to the above-listed protocol. The proposed changes to the protocol have been acknowledged as not increasing the risk toward study participants. The protocol may continue under an Exempt determination status.

A copy of this communication will be maintained in the study file. The amendment application status will show withdrawn.

Note: Any proposed changes to "Exempt" level studies, including those to study materials should be communicated to the IRB Program Coordinator through e-mail. We will work together to determine if an online amendment application will be required.

I wish you much success with your research.

Thank you,

Meghan Hammock

IRB Program Coordinator

Office of Research Support & Compliance

Phone: 512-232-2625

Fax: 512-471-8873

Coordinator Hours: Monday- Friday 7:30 a.m. – 4:30 p.m. CST

IRB USE ONLY
Study Number: 2016-08-0079
Approval Date: 11-08-16
Expires: 11-07-19
Name of Funding Agency (if applicable): Southern Nursing Research Society; Cain Center for Excellence in Nursing Research; Robert Wood Johnson Foundation

Consent for Participation in Research

Title: Well-Being of Adults with Disabilities living in Rural Texas: A Grounded Theory

Introduction

The purpose of this form is to provide you information that may affect your decision as to whether or not to participate in this research study. The person performing the research will answer any of your questions. Read the information below and ask any questions you might have before deciding whether or not to take part. If you decide to be involved in this study, this form will be used to record your consent.

Purpose of the Study

You have been asked to participate in a research study about the meaning of well-being to adults with disabilities. The purpose of this study is to investigate factors that influence the choices related to health and social engagement made by adults with disabilities.

What will you be asked to do?

If you agree to participate in this study, you will be asked to:

- Complete a short questionnaire regarding demographics
- Complete the Kessler Psychological Distress Scale (K6) 6-item survey
- Complete the ICECAP-A 5-item survey

- Meet with the researcher to discuss your health, your relationships with friends and families, and your community.

You will be asked to meet with the researcher from one to three times for 60 to 90 minutes at a time. The date and location of the meetings will take place in a location that is mutually agreeable. The study will include around 30 adults with disabilities.

Your participation will be audio recorded.

What are the risks involved in this study?

There are no foreseeable risks to participating in this study.

What are the possible benefits of this study?

You will receive no direct benefit from participating in this study; however, there is potential benefit to society from the knowledge gained. There are also possible therapeutic benefits of sharing your stories with the nurse researcher.

Do you have to participate?

No, your participation is voluntary. You may decide not to participate at all or, if you start the study, you may withdraw at any time. Withdrawal or refusing to participate will not affect your relationship with The University of Texas at Austin (University) in anyway.

If you would like to participate, please sign. You will receive a copy of this form.

Will there be any compensation?

You will receive $25 per interview. Payments will occur at the beginning of each research interview. You will be responsible for any taxes assessed on the compensation.

How will your privacy and confidentiality be protected if you participate in this research study?

Your privacy and the confidentiality of your data will be protected by the following steps:

- You will be involved with selecting the location for research interviews, and you will have control over the amount of information you choose to share.
- No personally identifiable data will be included with either the audiotapes or transcripts.
- Your name will only appear on the informed consent document. This document will be stored in a locked file separate from the audiotapes and transcripts.
- Any identifying information included in any transcript will be deleted.
- You will be assigned an ID number at the beginning of the study. This number will be used instead of your name on all research materials. The list linking participant names and ID numbers will be stored in a locked file cabinet separately from other research materials and will be destroyed when the study ends.

If it becomes necessary for the Institutional Review Board to review the study records, information that can be linked to you will be protected to the extent permitted by law. Your research records will not be released without your consent unless required by law or a court order. The data resulting from your participation may be made available to other researchers in the future for research purposes not detailed within this consent

form. In these cases, the data will contain no identifying information that could associate it with you, or with your participation in any study.

If you choose to participate in this study, you will be audio recorded. Any audio recordings will be stored securely and only the research team will have access to the recordings. Recordings will be kept for 3 years and then erased.

If the researcher should observe or otherwise learn of child or elder abuse while visiting your home, your confidentiality will be broken. We are required by law to report child or elder abuse to relevant agencies (Child Protective Services or the Texas Department of Family and Protective Services). If this situation occurs, it will be reported.

Whom to contact with questions about the study?

Prior, during or after your participation you can contact the researcher Whitney Thurman, RN, MSN at 512-657-3855 or send an email to wthurman@utexas.edu for any questions or if you feel that you have been harmed.

This study has been reviewed and approved by The University Institutional Review Board and the study number is **2016-08-0079.**

Whom to contact with questions concerning your rights as a research participant?

For questions about your rights or any dissatisfaction with any part of this study, you can contact, anonymously if you wish, the Institutional Review Board by phone at (512) 471-8871 or email at orsc@uts.cc.utexas.edu.

Participation

If you agree to participate, please sign and date this form, and return to the researcher. You will receive a copy for your records.

Signature

You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time. You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

_____
Printed Name

_____ _____
Signature Date

As a representative of this study, I have explained the purpose, procedures, benefits, and the risks involved in this research study.

_____
Print Name of Person obtaining consent

_____ _____
Signature of Person obtaining consent Date

Participant ID _____
Date _____

Demographic Information

1. What is your age?

2. What is your ethnicity?

3. In what county in Texas are you currently living? For how long have you lived there?

4. From the list below, what is your current marital status?
    a. Married
        i. How long?
        _____
    b. Divorced
        i. How long?
        _____
    c. Live with significant other
        i. How long?
        _____
    d. Widowed
        i. How long?
        _____
    e. Never married

5. What is your highest level of education?

Participant ID _____
Date _____

6. Do you currently have paid employment?

   If yes, please list your occupation:
   _____

   If no, are you seeking paid employment?
   _____

7. If you have paid employment, looking at the options below, what type of employment do you have?
   a. Full-time (40 hours per week or more)
   b. Part-time (less than 40 hours but more than 20 hours per week)
   c. Part-time (20 hours per week or less)
   d. Seasonal (I work during certain seasons of the year but not all the time.)
   e. As needed (I only work for pay as needed.)

8. From the list below, what is your approximate annual income?
   a. Less than $10,000
   b. $10,000-$15,000
   c. $15,000-$20,000
   d. $20,000-$25,000
   e. $25,000-$35,000
   f. $35,000-$50,000
   g. $50,000-$75,000
   h. $75,000 or more

Participant ID _____
Date _____

9. From the list below, what type of health insurance do you have? Select all that apply.
    a. No insurance
    b. Private pay insurance
    c. Private pay insurance through my employer
    d. Medicare
    e. Medicaid
    f. VA benefits
    g. Tricare
    h. I am not sure

10. From the list below, in what type of residence do you live?
    a. I own my own home
    b. I own my own condominium
    c. I rent a home
    d. I rent an apartment
    e. I live with family in their home
    f. I live with family in their apartment
    g. I am currently without a place to live
11. For how long have you lived in your current place of residence?

12. What best describes your living arrangement? Please choose all that apply.
    a. I rent
    b. I own my residence
    c. I live in government assisted housing
    d. My family helps to pay my living expenses

13. How many people currently live with you?

Participant ID _____
Date _____

14. Do you have children?
    a. If yes, how many children do you have?
       _____

    b. If yes, how old are your children?
       _____

15. Do you have grandchildren?

    a. If yes, how many grandchildren do you have?
       _____

    b. If yes, how old are your grandchildren?
       _____

16. At what age were you when you were told by a doctor that you had an illness, disability, or other condition that would not go away?

ABOUT YOUR OVERALL QUALITY OF LIFE

Please indicate which statements best describe your overall quality of life at the moment by placing a tick (✓) in **ONE** box for each of the five groups below.

1. Feeling settled and secure		
I am able to feel settled and secure in **all** areas of my life	☐	4
I am able to feel settled and secure in **many** areas of my life	☐	3
I am able to feel settled and secure in **a few** areas of my life	☐	2
I am **unable** to feel settled and secure in **any** areas of my life	☐	1

2. Love, friendship and support		
I can have **a lot** of love, friendship and support	☐	4
I can have **quite a lot** of love, friendship and support	☐	3
I can have **a little** love, friendship and support	☐	2
I **cannot** have **any** love, friendship and support	☐	1

3. Being independent		
I am able to be **completely** independent	☐	4
I am able to be independent in **many** things	☐	3
I am able to be independent in **a few** things	☐	2
I am **unable** to be at all independent	☐	1

4. Achievement and progress		
I can achieve and progress in **all** aspects of my life	☐	4
I can achieve and progress in **many** aspects of my life	☐	3
I can achieve and progress in **a few** aspects of my life	☐	2
I **cannot** achieve and progress in **any** aspects of my life	☐	1

5. Enjoyment and pleasure		
I can have **a lot** of enjoyment and pleasure	☐	4
I can have **quite a lot** of enjoyment and pleasure	☐	3
I can have **a little** enjoyment and pleasure	☐	2
I **cannot** have **any** enjoyment and pleasure	☐	1

Please ensure you have only ticked **ONE** box for each of the five groups.

K6+

Provider: _____

Provider ID:

Date completed: __ __ / __ __ / __ __ __ __

Please used gummed label if available

Patient or Client Identifier:

Surname:

Other names:

Date of Birth: Sex:

__ __ / __ __ / __ __ __ __ Male ☐1 Female ☐2

Address:

The following questions ask about how you have been feeling during the **past 30 days**. For each question, please circle the number that best describes how often you had this feeling.

Q1. During the past 30 days, about how often did you feel …	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a. …nervous?	1	2	3	4	5
b. …hopeless?	1	2	3	4	5
c. …restless or fidgety?	1	2	3	4	5
d. …so depressed that nothing could cheer you up?	1	2	3	4	5
e. …that everything was an effort?	1	2	3	4	5
f. …worthless?	1	2	3	4	5

Please turn over the page to continue

Q2. The last six questions asked about feelings that might have occurred during the past 30 days. Taking them altogether, did these feelings occur More often in the past 30 days than is usual for you, about the same as usual, or less often than usual? (If you never have any of these feelings, circle response option "4.")

More often than usual			About the same as usual	Less often than usual		
A lot	Some	A little		A little	Some	A lot
1	2	3	4	5	6	7

The next few questions are about how these feelings may have affected you in the past 30 days. You need not answer these questions if you answered "None of the time" to **all** of the six questions about your feelings.

Q3. During the past 30 days, how many days out of 30 were you totally unable to work or carry out your normal activities because of these feelings?

_____ **(Number of days)**

Q4. **Not counting the days you reported in response to Q3**, how many days in the past 30 were you able to do only half or less of what you would normally have been able to do, because of these feelings?

_____ **(Number of days)**

Q5. During the past 30 days, how many times did you see a doctor or other health professional about these feelings?

_____ **(Number of times)**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Q6. During the past 30 days, how often have physical health problems been the main cause of these feelings?	1	2	3	4	5

Thank you for completing this questionnaire.

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